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An exploration of the lives of disabled people
sexually abused in childhood: “the double
whammy effect.”

Martina Higgins

PhD
2006

ABSTRACT

This thesis investigates the lives of seven disabled people who were sexually abused in childhood by utilising narrative methodology and the application of the social model of disability. Flexible methods of participation were offered to participants and continuous ethical evaluation formed the backbone of the research relationship. Thematic analysis generated three interlocking and overarching “grand” themes that constituted the substantive chapters of the thesis (power, identity and narrative) and provided a structure within which the findings were embedded.

Narratives of power illustrate how the sexually abused disabled child is potentially located at the collision point of a number of oppressive societal beliefs and practices related to the treatment of both children and disabled individuals. These debilitating attitudes become apparent in the workings of certain organisational structures and the general functioning of some family environments.

Narratives of identity deals with the issue of how a, sometimes, fragile identity created by disability oppression becomes fragmented by the sexual abuse experience. It also illustrates that from this compromised starting position, participants have been able to forge a series of self-affirming collective identities.

The chapter entitled **narratives of the narrative** concerns itself, ostensibly, with the reconstruction of the abuse narrative. Within this chapter it can be seen that when the usual defence mechanisms (dissociation) become less necessary for survival, and when the external triggers are prevalent, the sexual abuse narrative emerges creating narrative chaos (Frank, 1995) and emotional destabilisation. The personal healing process has involved the reconstruction of a more reflective, self-absolving and coherent version of events, which contains narrative truth (Spence, 1994).

In concluding this thesis, several tasks were undertaken including the weaving together of the complex relationship between disability and child sexual abuse, and a highlighting of the key pressure points where difficulties were exaggerated. It also involved: consideration of whether narrative methodology fulfilled its purpose, a reflection on the work's theoretical positioning and the implications of the thesis for policy and practice.

Keywords

Social model of disability, emancipatory disability research, narrative, child sexual abuse, disabled children, ethics, paedophiles, organisations, power, identity, dissociation, narrative reconstruction

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ACKNOWLEDGEMENT

My thanks go to Professor John Swain and Dr Maureen Gillman for providing a consistently supportive, thoughtful and thought-provoking supervision experience throughout the past five years. Additionally, I need to thank Jim and Holly who have also offered encouragement, despite my frequent periods of introspection and the “dreaded” visits to York University library after school! I would also like to acknowledge the contributions of Merry Wahogo who has assisted me in my “thinking through” of some of the issues. Finally, and most importantly, a huge thanks go to Lyn, Lizzie, May, Jean, Chloe, Thomas and Josh who have made this thesis possible and who have inspired me by their courage and determination.

AUTHOR'S DECLARATION

This thesis has not been submitted for any other award, and has not been produced in collaboration with any other individual. At the time of writing, a version of the research has been submitted as a chapter for a book edited by John Swain and Sally French.

INTRODUCTION

Child sexual abuse is a controversial aspect of human relations, which has attracted attention of a conflicting nature, both within the media and academic circles. For every child disclosure, there are a series of organisational structures and practices that seek to undermine it, for every adult testimony there are a number of societal discourses that work to discredit it. For those minorities who are brave enough to “speak out” and expose their realities, the challenges presented are great. Disabled children, who are at increased risk of abuse, face extra barriers when telling their story in comparison to their non-disabled peers. These barriers are both impairment related and attitudinal. This thesis represents the experiences of seven disabled people who decided, for various reasons, to take the risk and share their life stories. Their narratives illustrate their personal determination and tenacity as they continue to overcome the consequences of their oppression and as they endeavour to raise the profile of a neglected and under-researched area of human existence. Their stories have offered rich research data, which demonstrates the complex inter-relationship between disability and child abuse.

In **Chapter One** I situate myself in relation to the subject area, locate the research, define a number of key terms and deconstruct some of the basic assumptions that lay the foundation for the thesis. In **Chapter Two**, the methodology chapter, the political and ideological base of the thesis is discussed, and the research methodology and its ethical complexities are examined. This chapter also includes an exploration of the process of research production, a consideration of the orientation of the analysis and a brief introduction to the seven research participants.

Within **Chapter Three**, and by drawing upon some of the assumptions addressed in Chapter One, the issue of power is addressed, with participants’ narrative episodes highlighting some of the objectifying practices that exist within certain organisational structures. Some of these practices involve child

abuse but others were symbolic of their devalued status within these establishments. The chapter also illustrates how these social and cultural attitudes can infiltrate the workings of family life, influencing both the actions of the perpetrators and the type of parenting experienced.

Chapter Four is concerned with the impact of child sexual abuse and disability on identity formation and identity enactment. It commences with an examination of a number of collective identities which participants have assumed, either partially or more fully in adult life. In particular, there has been consideration of issues relevant to the survivor identity, a disability identity and sexual identity. Working backwards, chronologically, some of the major defence mechanisms used by participants, in childhood, to survive their experiences are highlighted, and the influence of the non-abusing parent on the child's sense of safety is discussed.

Chapter Five builds on Chapter Four and investigates the abuse narrative and the impact that sexual abuse has had on a participant's ability to produce a coherent narrative account of the self. It begins with a consideration of the current work being undertaken by individuals, both in terms of co-constructing a more accurate account of past events and a re-working of the losses that have been incurred as a result of their experience. Working backwards, again, the chapter explores the point at which participants were forced to re-engage with, and make sense of, their dissociated sexual abuse narrative. As well as demonstrating the existence of varying degrees of remembering, this chapter also includes examples of recovered memory from a prior state of dissociative amnesia and the range of discourses that surround this experience. It raises the issue of narrative truth and narrative credibility and explores, for one individual, the impact of impairment on personal ownership of their own abuse narrative.

The thesis concludes with a general analysis of the data encompassed within the chapters, drawing particular attention to the enmeshed relationship between disability and child sexual abuse. It discusses the ways in which participants have worked to produce a different type of story and identifies

some of the ethical dilemmas and ongoing concerns presented for my self, as researcher. The conclusion evaluates some of the “grand theories” used in this piece of work and the predominance, overall, of a social constructionist perspective. It identifies the ways in which this research has extended the current academic discourse surrounding this subject area, identifying the limitations prevalent in other discourses. The conclusion finishes with reflection on the implications of participants’ narratives for current policy and practice.

CHAPTER ONE: LOCATING THE RESEARCHER AND RESEARCH, DEFINING TERMS AND DECONSTRUCTING ASSUMPTIONS

I begin this chapter with the provision of a comprehensive autobiographical account, which endeavours to situate myself as a researcher and define my personal relationship to this thesis. The objective here is to illustrate the dynamic relationship between the researcher, the research participants and the production and analysis of the data.

I then offer an overview of research literature relevant to this thesis. This presentation of material does not constitute a “traditional style” literature review since this process has been encapsulated within the individual chapters, where the specifics of the data have produced the starting point from which the relevant literature has been generated and analysed. Instead, as indicated, this section is purely a synopsis of related background research, offering a general context for the subject under investigation.

The chapter then goes on to provide a “glossary type” presentation of several of the key concepts that are utilised within this piece of work, in an attempt to reduce speculative associations and possible misunderstandings. Following on from this clarification, I discuss the major assumptions that underpin the thesis and provide a meaning-making function in terms of its conceptualisation and political positioning. Of relevance are societal perspectives on child abuse and impairment and, in particular, the evaluative substance embodied in these concepts. Also incorporated is an individual perspective on the question of “narrative truth,” a standpoint that is personally and professionally located and which has determined how the participants’ narrative accounts have been accepted and evaluated.

a. Locating the researcher

In terms of providing the context for this piece of work, I believe it necessary to situate myself. This is because I believe it to have some relevance to why I became interested in this particular subject area in the first instance, and how I conducted the research. Since my upbringing has had some bearing, it is probably best to start there. I was born in the north of England to Irish Catholic parents who had emigrated to this country in their mid to late teens as part of the generalised mass exodus of young people from the farming communities in southern Ireland. The presence of the Catholic Church was a pervasive feature of family life with the expectation of regularly attending church and partaking in its associated rituals. Part of this upbringing, and typical of that generation and culture, was the sanctioning of physical chastisement, the unquestioned belief in its appropriateness and the lack of regard for its consequences.

I left home to undertake undergraduate studies and, because of this type of family background, struggled with the process of separation and individuation. This resulted in acquiring an eating disorder, probably, of a non-serious nature but which, nevertheless, influenced my life for the subsequent four to five years. In 1984, I became a graduate and a qualified social work practitioner, and there then followed several jobs as a general childcare social worker for a local authority and a more specialist post with the NSPCC, which involved the investigation of child abuse. This team had a particular remit to work, both individually and in groups, with children and adult survivors of child sexual abuse. It was this post and the bravery of survivors who were intent on “getting through it” that produced an interest in this particular subject area and inspired the research.

In 1994, when working as a social work manager and midway through a psychoanalytical psychotherapy clinical training, I was diagnosed with multiple sclerosis, which created a “narrative chaos.” Looking back, it is impossible to underestimate the significance of this event in terms of my own personal

narrative. Within several years I had swung from a personal and political perspective influenced by medical model ideology to an eye opening and empowering social model perspective. This transition was related, essentially, to the birth of my daughter who was born with a visual impairment and my encounters with other disabled people who I actively sought out to help me make sense of the experiences of the previous three years. During that time I had also retired from social work and begun a master's degree in women studies, this latter experience consolidating a personal commitment to feminist politics, which has been influential in terms of data analysis in this thesis. What the experience did do, however, and in a more negative way, was highlight my status as an individual operating on the margins of the marginalised; a phrase coined by one of my research participants. In positive terms, it precipitated a need to become a member of a disabled people's coalition, which brought me into contact with other disabled women, some of whom also felt excluded by feminist politics and others who had little interest in the issue.

Choosing to write about this particular subject area is a conflation of my personal, political and professional experiences. An interest in children's rights, which includes a right to both physical and emotional well-being, has derived from the harm created by a commonplace and objectifying childcare regime. The social model of disability, as well as providing the orientation of this study, provides an ongoing contextualisation that helps me negotiate difficult encounters with the non-disabled community. Career choices, job opportunities and clinical training have, additionally, provided the opportunity for self-reflection and personal growth.

During my time as a social worker, child protection and disability were viewed as two separate specialisms with a certain degree of neglect for the overlap. This thesis is an attempt to draw out that relationship, investigate its oppressive constituents and widen public thinking in the area. As a disabled person, I am now acutely aware of the ways in which we are marginalised in our interpersonal relationships and in our general encounters in wider society. I have personal experience of the negative attention we can attract, the

manifestations of the hostility of others and the dangers these present in terms of our own internalised oppression. My experiences of disability have helped me forge a link with my research participants, get under the skin of this subject area and present it with the urgency that it requires. It has also influenced my attempts to achieve the emancipatory research ideal, a finding on which only participants can comment.

b. Locating the research

There have been a significant number of prevalence studies looking at the sexual abuse of children, originating predominantly from North America. Itzin (2000a) cites two of the more credible reviews of this literature: Bolen and Scannapieco (1999) and Russell and Bolen (2000), and concludes that both studies provide prevalence estimates that fall in a range of 30% to 40% for female child sexual abuse and 13% or more for male child sexual abuse. Literature that specifically focuses on the prevalence of abuse amongst disabled children has been limited. Westcott and Jones (1999) attribute this neglect of academic evaluation to societal indifference regarding the subject matter. They believe that devaluing assumptions contribute to a situation whereby disabled children are at an increased risk of child sexual abuse, yet the lack of related research continues. This is a factor also highlighted in the work of Zavirsek (2002).

Most of the work that has investigated the prevalence of child sexual abuse among disabled children has taken place, again, in North America and has been derived from retrospective prevalence studies looking at abuse in general. One of the most commonly cited, large-scale studies is that of Sullivan and Knutson (2000), which is a replication and extension of their previous work (Sullivan and Knutson, 1998) involving a merger of relevant databases. The study found that disabled children are 3.14 times more likely to be sexually abused than non-disabled children, which supports the findings of previous American research (Jaudes and Diamond, 1983; Crosse, 1993; Knutson and Sullivan, 1993; Sobsey and Mansell, 1994). It concludes that

children with behavioural difficulties, speech and language issues and learning difficulties were more at risk of sexual abuse than other disabled children.

Kvam (2004) investigated the prevalence of child sexual abuse in Norway, specifically amongst individuals with hearing impairments, finding similar incidence figures with half of the research participants reporting that the abuser also had a hearing impairment and that half of the abusive events took place in special schools for the deaf (*sic*). These individuals also reported fewer friends at home, bullying experiences at school and poor parental relationships compared to the non-abused hearing impaired group.

In terms of gender differentials, Sobsey et al. (1997), by using data collected from the National Centre on Child Abuse and Neglect in the USA, found that significantly more disabled girls (62%) than boys (38%) had experienced sexual abuse but that boys formed a significant larger minority compared to non-disabled sexually abused boys. Looking more closely at the group of sexually abused boys, Sobsey et al. found that more disabled boys were sexually abused in the 6-11 age range compared to disabled girls in that same age grouping.

With respect to the UK, there is a paucity of national prevalence data, which relates to the fact that the government's own figures on child sexual abuse are collated from the regional child protection registers which do not necessarily indicate whether a child has an impairment (Westcott and Cross, 1996). In a postal questionnaire sent to 121 chairs of Child Protection Committees in the UK, enquiring about the recording of a child's impairment once a child's name is added to the child protection register, only 14% of authorities could give an actual figure (Cooke and Standen, 2002).

Two of the most commonly cited UK studies that provide some incidence data relating to the sexual abuse of disabled children are that of Kennedy (1989) and Sinason (undated). Kennedy looked specifically at children with hearing impairments who were known to the teachers and social workers of children

with hearing impairments. Sinason's cohort included children with learning difficulties and emotional problems who were in therapy with her (Westcott and Cross, 1996). Bearing in mind methodological bias, both samples reported a high incidence of child sexual abuse. Overall, it seems that research in the UK on the sexual abuse of disabled children is limited with the majority of research being conducted through discussion with professionals known to the child, such as teachers, social workers, residential care staff, (Stuart-Green and Stone, 1996) or via retrospective case note review (Balogh, Bretherton, Whibley et al., 2001).

Whilst research involving non-disabled participants who were sexually abused in childhood (and examining differing facets of the abuse experience) is plentiful, the same can not be said for research on sexually abused disabled people. Probably, one of the most commonly cited pieces of UK research addressing the issue of abuse and disability is that of Westcott (1993). This study is a generalised piece of work looking at the abuse of disabled adults and children using semi-structured interviews where, amongst other things, the disabled participants themselves pinpoint factors that contributed to their increased risk of abuse. A similar situation exists in relation to narrative based research. Increasingly, narrative methodology is used to investigate the sexual abuse experience and its far-reaching impact on the non-disabled individual's life (Boone James, Liem and O'Toole, 1993; Scott, 1998; Itzin, 2000b; Pearce, 2000; Edwards, 2000; Durham, 2003; Overlien and Hyden, 2003). Yet for disabled people, who were at increased risk in childhood, there is a notable absence of this type of work. The limited amount that does appear (Zavirsek, 2002) does so outside the UK.

This particular piece of research aims to contribute to this limited field of study and illustrate the complexity of individual experience and the strength of character demonstrated by a group of disabled individuals who strive to rise above their oppression. The specific focus on sexual abuse does not negate the analysis of other aspects of child abuse experienced by the participant and common in such situations (Sullivan and Knutson, 2000). Nor does it detract from an analysis of the abuse of others witnessed by the participants

or, in fact, the more generalised abuses/misuses of power experienced in differing organisational settings. The focus does, however, represent a particular need to consider, for example, the enmeshed relationship between child sexual abuse, the impaired body and identity (particularly sexual identity), a relationship which has been of great significance for all participants.

c. Defining terms

Within this section, I endeavour to define some of the key terms that are used frequently within this thesis and which may need some additional clarification in terms of the meaning intended.

i) Abuse

Ayres and Woodtli (2001), when investigating abuse by carers, define abuse in terms of the “wrongful or unreasonable treatment (of another) by word or deed” and that mistreatment, ill treatment or maltreatment refers to the “infliction of injury, usually physical, with the deliberate intent to harm.” The term abuse, as it applies to child sexual abuse, although seemingly straightforward in definitional terms has presented a number of difficulties for professional practitioners working within the field. Definitions range from broadly based constructs employed by clinicians to narrow prescriptive constructs employed by the legal profession. The process of arriving at a consensus of opinion is hampered by society’s inability to agree where the dividing line stands on a continuum of behaviours that range from non sexually abusive to clearly sexually abusive, complicated even further by the fact that differing contexts provide differing interpretations of behaviours (Haugaard, 2000). For the purpose of this research, I have used a broad based definition, which draws from both Berliner and Elliot (2002, page 55) and the Department of Health guidelines (1999, page 7). It reads as follows:

“Sexual abuse involves any sexual activity with a child where consent is not or cannot be given. This includes sexual contact that is

accomplished by force or threat of force, regardless of the age of the participants, and all sexual contact between adult and child, regardless of whether there is deception, or the child understands the sexual nature of the activity. Sexual contact between an older and a younger child can also be abusive if there is a disparity in age, development, or size, rendering the younger child incapable of giving informed consent. Sexually abusive activities may involve physical contact, including penetrative or non-penetrative acts. They may also include non-contact activities, such as involving children in looking at, or in the production of, pornographic material, watching sexual activities, or encouraging children to behave in sexually inappropriate ways.”

My definition also includes any act that the participant themselves considers to be sexually abusive. The thesis also acknowledges that other forms of child abuse, such as physical abuse, co-exist (Dong et al., 2004) and that emotional abuse and its psychological manifestations are implicit when trying to understand both the short-term and long-term consequences of sexual abuse. Of particular relevance, here, is Glaser’s typology (2002), which identifies a number of different forms of emotional abuse, all of which I consider to be associated with the child sexual abuse experience. Glaser proposes that these manifestations of emotional abuse can be observed in the following adult behaviours:

- Emotional unavailability, unresponsiveness and neglect
- Negative attributions and misattributions to the child
- Developmentally inappropriate or inconsistent interactions with the child
- Failure to recognise or acknowledge the child’s individuality and psychological boundary
- Failing to promote the child’s social adaptation

As regards the specifics of the sexual abuse experience, I have not made the assumption that one particular set of sexually abusive behaviours has a more serious effect than others. The reality of the situation lies in the subjective experience of the individual and its deleterious impact on functioning in both childhood and adulthood (Archard, 1993).

The application of the word “abuse” has also been used within this thesis, and particularly in the chapter on power, to describe a range of organisational practices where participants believed they had been treated in a manner that could be considered to be “less than human.” Whilst others may see these practices as professional shortcomings relating to resourcing issues, for example, participants had experienced them as inherently abusive in a number of ways. In medical settings, some participants had experienced objectifying treatments considered to be either invasive of their personal/psychological boundaries, or unnecessarily painful. In educational settings, they encountered objectifying systems that sanctioned behaviours such as: failing to protect the child from bullying by their non-disabled peers, failing in their responsibility to actively engage in the child protection process and, perhaps more controversially, depriving the child of the opportunity to achieve their academic potential. Similarly, narrative accounts of involvement with other agencies, such as social services, also reflected misuses of organisational power. Within the chapter on power, and when considering organisational power, in particular, I have used the terms “misuse” and “abuse” as interchangeable concepts since I believe that they sit on the same continuum of behaviours, with conscious intentionality playing a part in their location on that continuum.

ii) Discourse, deconstruction and reconstruction

These concepts are derived from, and are associated with, social constructionist theory, which problematises the taken for granted ways of understanding the world embodied in essentialist thinking (Burr, 2003). Social constructionist philosophy offers, instead, a more critical analysis of traditional normative classification and the perceived realities that accompany them. Correspondingly, and within this piece of work, the term “discourse” relates to the linguistic practices that surround any one particular object or version of events. As Burr (2003) writes, discourse is historically and culturally located and regulates our knowledge of the world with certain discourse, particularly those embedded in a scientific or medical base, being given more credibility than others and granting a licence to act in specific ways. In that respect, and

according to Foucault (1980), knowledge, and its associated discourse and perceived truths, confers privilege and power. Deconstruction relates to an analysis of an idea or event with the intention of exposing the oppositional discourse operating within it. As White (1993) writes:

“...deconstruction has to do with procedures that subvert taken for granted realities and practices: those so called truths that are split off from the conditions and the context of their production; those disembodied ways of speaking that hide their biases and prejudices; and those familiar practices of self and of relationship that are subjugating of persons’ lives.”

(White, page 34)

This thesis attempts to highlight and deconstruct some of the pervasive and often oppressive discourses that relate to both disability and child abuse. This diminishing discourse permeates the structures of society and is particularly prevalent in certain societal institutions. It has influenced the construction of identity, and the production of personal narratives, for all of the participants in this study. The term reconstruction, as it appears in relation to narrative, relates to the processes by which all of these individuals have attempted to confront devaluing discourse, deconstruct its constituents and produce a more reflective and self-validating personal narrative account, which contains a narrative truth.

iii) Dissociation, transference, counter-transference and projection.

Although this thesis offers a social constructionist overview, I have utilised, where relevant, theorisation of a psychodynamic or psychoanalytical nature. This type of discourse has been applied, in Chapter Four, to the individual’s defence mechanisms when dealing with the trauma of child sexual abuse (dissociation). It has also been applied, in Chapter Five, to the de-valuing discourse aimed at undermining recovered memory (false memory syndrome), and to the qualities of some therapeutic encounters, which become enactments of primary relationships (transference and counter-transference). Additionally, it has been applied in Chapter Three, to the dynamics that can be associated with the interactions of disabled and non-

disabled individuals (projection). Here I offer further clarification by drawing on the work of van der Kolk, van der Hart and Marmar (1996), and Laplanche and Pontalis (1988):

- **Dissociation** refers to the narrowing of consciousness with a focus on central perceptual details. The traumatic event becomes split off from ordinary consciousness and cannot be transformed into a neutral narrative. Self-destructive dissociative behaviours frequently accompany the trauma of child sexual abuse. In some situations, the narrowing of consciousness can evolve into complete amnesia, otherwise referred to as dissociative amnesia (van der Kolk et al., page 307). Dissociative amnesia has also been referred to, in other parts of this text, as repressed memory. False memory syndrome is a concept that emerged in the early 1990s as a societal attempt to undermine the narratives of survivors who had repressed and later recovered their memory of child sexual abuse.
- **Transference** is a concept that is generally, but not exclusively, applied to psychotherapeutic encounters. In the transference, infantile wishes and demands re-emerge and are experienced with a strong sensation of immediacy (Laplanche and Pontalis, page 455).
- **Counter-transference** refers to the reaction of an individual to the other's transference. If occurring in a therapeutic encounter, this counter-transference response can be used as an analytical tool (Laplanche and Pontalis, page 92).
- **Projection** has wide usage and can be seen to operate both inside and outside therapeutic relationships. Within this thesis, it is used to describe the psychological displacement of a feeling, which is expelled from the subject and relocated in another person (Laplanche and Pontalis, page 349).

iv) Impairment and disability

This thesis makes a clear distinction between impairment and disability and further discussion on this point can be seen in Chapter Two, page 23. Using the social model of disability, impairment essentially relates to the individual's physiological condition, whilst disability is about disabled people's exclusion within society (Barnes, 1996).

d. Deconstructing assumptions

As a consequence of adopting a social constructionist perspective, it is firstly necessary to make explicit some of the main societal assumptions, relating to disability and child abuse, which lay the foundations for this piece of work. The manifestations of these societal assumptions, as can be witnessed in the behaviour and attitudes of others, have affected the participants' lives in numerous ways and all have had some relevance to my own professional background, political beliefs and personal life experiences. A certain amount of "testing out" of the meaning embodied within these assumptions took place between most participants and myself in the early stages of the research process. These assumptions created a context for the discourse that ensued. Following on from this, I will discuss the issue of "narrative truth" and how this has been understood and evaluated within this piece of work. Since this jointly constructed meaning underpinned the three substantive chapters, it seems essential to unpack these assumptions and discuss them in more detail.

i) Impairment and contemporary society

This thesis starts from an assumption that disabled people, in general, are a devalued section of society commonly experiencing prejudicial treatment by non-disabled people, which is rooted in ignorance, lack of awareness and fear of difference (Grewal et al., 2000). Writers, such as Drake (1996), argue that the power to devalue certain sections of society, such as disabled people, lie in the status of the dominant group within that society. This dominant group

produces societal norms and categorises those who fall outside these norms as other/abnormal. For disabled people, notions of bodily perfection, interpreted in non-disabled terms, is considered to be one of the ideals towards which all members of society should aspire. It hangs like an albatross around many disabled people's necks by creating one of the major sources of our oppression (Barnes, 1996). Thompson (2003) offers a useful categorisation of mechanisms, which serve to maintain the hegemony of the dominant group and devalue and oppress others. Amongst other things, these mechanisms can include: negative stereotyping, marginalisation, infantilisation, medicalisation, dehumanisation and trivialisation.

Stereotyping continues to be one of the major processes complicit in maintaining disabled people's devalued status. By nature, and according to Thompson (2003), stereotypes are so ingrained within our culture that it is easy to become oblivious to their existence and how they shape perceptions. They are embedded within general discourse and work in an insidious fashion to strengthen the negative attitudes of non-disabled people (French, 1996) and erode the confidence of the disabled individual (Reeve, 2002). For disabled people, a range of offensive and depersonalising stereotypes persist (Sutherland, 1981), which then attract a set of habitual devaluing practices from non-disabled people (and, occasionally, disabled people from other impairment specific groups). Davis (2004) writes that, similarly, disabled children are depicted in negative, inaccurate and devaluing terms. They are often portrayed as asexual and passive individuals who are incapable of making choices and are unlikely to progress to independent adulthood.

Contemporary cultural imagery of impairment builds on stereotypes and continues to centre round notions of tragedy and lack of agency. This imagery has remained largely unchallenged until very recently. The tabloid press, according to Priestley (1999), generally focus on a limited number of impairment related issues such as "personal interest stories." Here, typically, there is a patronising depiction of the disabled person as "triumphing in the face of adversity" or surviving as a result of a non-disabled person's generous donations of cash/body parts. Shakespeare (1997) also believes that charity

advertising operates along similar lines. Classically, disabled people are represented in a demeaning and pitiable light with power differentials being widened by inflating non-disabled people's egos, often at the cost of disabled people's integrity. For disabled women, as Sheldon (2004) argues, the negative stereotypical representation of femininity, which also alludes to passivity and dependency, is compounded by a perceived failure to be able to compete for other professed feminine necessities relating to appearance, relationship formation and parenting.

Clarke and Marsh (2002) examine the negative terminology concerning disability, which has evolved from stereotyping and continues to have a corrosive effect on disabled people's self-esteem. Such terminology, they believe, fulfils a patriarchal need to distance and oppress disabled people. Some participants in this study experienced the use of disabling language, particularly at school, where the word "spaz" was used as a playground taunt in mainstream school. Similarly, some also experienced prejudices in their interactions with non-disabled peers in the workplace. For many disabled people, who are on the receiving end of this continuous process of invalidation, it is not surprising that one of the possible consequences is an acceptance and incorporation of society's prejudice into disabled people's own psyche so maintaining and perpetuating the power differential (Reeve, 2002). This is a process that many, if not all, participants in this study have fought hard against.

In terms of epistemological triangulation, and the further evaluation of disabled people's experiences, Grewal et al. (2000) attempted to undertake a systematic investigation of non-disabled people's attitudes towards disabled individuals by using in-depth interviews and discussion groups with large numbers of both disabled and non-disabled people. Not surprisingly, their findings mirrored disabled peoples' previously expressed views and concerns and, notwithstanding the methodological bias that inevitably exists in opinion-related research, they identified the power of the media, in particular, as a major contributory factor in perpetuating negative depictions of impairment. The majority of people felt that prejudice against disabled people was

common and that ignorance, lack of awareness and fear of difference was the primary reasons for prejudicial opinion.

ii) Childhood, child abuse and society

Similarly, this thesis also assumes that children are a devalued section of society and that the prevalence of such things as child abuse is symptomatic of this fact. The historical legacy of abusive and devaluing childcare practices, according to Hart (1991), rests in the notion of “children as property” with adults believing that they have absolute power over their children’s lives. Armstrong (2000) has plotted the historical development of societal attitudes towards child sexual abuse, in particular, whether it is incest or extra-familial sexual abuse. These attitudes range from overt acknowledgement of its acceptability, in sixteenth century Christianity, to its later denial and reinterpretation as childhood fantasies in the early 1900’s by Freud. More recently, and since the 1970’s when there was an identification of the “battered child syndrome” and the appearance of narrative literature on sexual abuse, a contradictory situation continues to exist in western society. Whilst there is an apparent social condemnation of child sexual abuse, the legal system continues to demonstrate a reluctance to prosecute perpetrators (Armstrong, 1983) and prevalence data illustrates that sexual abuse continues to be a significant global problem (Hamer, 2002).

In terms of understanding the broader societal context, controversial psychoanalytic author Alice Miller offers, I believe, valuable insight into the historical and social origins of child abuse. Her theories are grounded in the concept of “poisonous pedagogy” (Miller, 1983); a historical process passed down from generation to generation and only interrupted by therapeutic intervention or some other form of advocacy (Miller, 1984). Miller (1983) contends that advice about child rearing, including the use of violence, masks the needs of the adult who is usually convinced that they have the best interests of the child at heart. Miller (2000) argues that society at large continues to blame the victim and protect the adult by depicting children as fantasists and liars. The emergence of the False Memory Syndrome

Foundation in the early 1990's is a very clear illustration of a societal backlash against a growing literature on the subject, and fear relating to the potential destabilisation of the patriarchal power structure of the nuclear family (Gaarder, 2000). In fact, other feminist writers offer overtly sociological perspectives on the issue and continue to make the connection between male privilege and violence towards women and children, arguing that child sexual abuse is just one manifestation of this violence and that it is endemic to all patriarchal societies that prioritise the needs of men (Reavey and Warner, 2003). It can also be argued that child sexual abuse is sanctioned in more covert ways by the use of, for example, the erotic portrayals of children in advertising and a general cultural trend within western societies towards early child sexualisation (Scott et al., 1998).

Britain's ambivalence towards the issues of child abuse is perhaps best observed in the current debates surrounding the use of physical chastisement. Legislation sanctioning the use of "reasonable physical chastisement" on children by parents/carers has created the necessary ambiguity that allows abusive behaviour to remain largely unchallenged (Freeman, 1999). Despite relatively recent criticism from the European Court of Human Rights, Britain has withheld its position on the rights of adults to physically chastise children. It has, instead, paid lip service to these criticisms by outlawing "inhumane and degrading" punishments. Many would perceive these amendments to be wholly ineffectual and create enough leverage for solicitors and judges, with personal and cultural bias, to offer an adequate defence for adults accused of abusing children. Freeman (2000) argues that until a starting point is achieved where violence, in whatever form, is banned outright, with the utilisation of appropriate legal sanctions, children will remain devalued second-class citizens. The right of disabled children to protection is further compromised by attitudes towards impairment, and the associated organisational ambivalence towards the subject.

iii) Narrative “truth”

Unquestionably, professional practice and related politics have influenced how I have received participants’ narrative accounts. A belief in the rights of the child to be protected from abuse by adults is implicit in social work training. So too is a commitment to meaningfully engage with children in order to gain their trust and help them negotiate any difficulties they have to contend with. The therapeutic literature relating to direct work with children advises to listen and affirm what children have to say and is rooted in an understanding that children rarely lie about difficult family relationships. If they do, this use of fantasy is often seen as a reflection of the child’s attempt to escape their reality. According to Oaklander (1978), fantasy can sometimes signify fear, self-doubt, poor self-image and/or guilt and it is seen as the practitioner’s job, in a sense, to look further than what is initially presented and help the child to find a place where they feel safe enough to engage with their reality.

The truth, as it relates to disclosures of sexual abuse by children who have reached a position of being able to overcome the many obstacles that prevent them talking about their experience, has become an increasingly conflictual area of professional debate. Child protection social workers grapple with the necessity of incorporating increasingly legalistic frameworks, such as the *Memorandum of Good Practice* (Home Office and Department of Health 1992), into their work with children, needing to demonstrate along the way, the child’s capacity to distinguish between truth and lies (McCarron et al., 2004). If the child’s case proceeds to criminal proceedings, in addition to corroborative evidence, a range of developmental factors will dictate how the child delivers their narrative of abuse, which will then determine whether a juror will consider it to be a truthful account of events (Westcott and Kyman 2004).

Whilst there are rare occasions where children feel that they have no choice but to manufacture false allegations of sexual abuse (Oates et al., 2000), I strongly believe that children do not invent or create sexual abuse narrative. When they do reach a point of feeling able to “speak out” a whole range of systems actively conspires to discredit what they have to say. This social work

experience of helping young children to tell their story, and assisting adults to establish their narrative truth, has influenced how I have engaged with participants' narrative accounts. Most of the participants, in childhood, struggled to understand the experience, evaluate (consciously or unconsciously) whether it was safe to disclose and determine whether they would be believed or not. In adulthood, they have worked hard to arrive at their own personal understanding of the "truth" with recovered memory, flashbacks, recall memory, medical records and conversations with family and friends all playing a part in this reconstruction.

This process of piecing together the past has resulted in the production of a narrative which I have accepted, within that particular research encounter, on that particular day, as factual data. As will become more apparent in Chapter Two, where postmodernist theorisation becomes more applicable is in the continually changing nature of a narrative over time as new information is recovered, old information is re-evaluated and fresh interpretations are made. It also has relevance to the interactive qualities of the interview process, which dictate how, and how much of, the story is told. Overall, however, and within this piece of research, I was less concerned with the absolute "rightness" of the narrative and more preoccupied with its contribution to expanding society's understanding of this neglected subject area (Fox, 2003).

Having provided the context for this piece of research it is now time to consider, in Chapter Two, the research methodology that facilitated the production of the data.

CHAPTER TWO: NARRATIVES OF METHODOLOGY

The following chapter on methodology attempts to deconstruct all aspects of the research mechanism. It begins with an overview of social model theory, a perspective which offers an alternative way of viewing disability, and which determines how the sexual abuse of disabled children is understood in the context of this thesis. Its application has also been relevant to personal practice principles, where emancipatory research ideals have driven a need to create flexibility and keep issues of empowerment/disempowerment continually on the agenda. In terms of the research method, this chapter discusses the use of a narrative methodology and its ability to capture the complexity and uniqueness of each individual participant's experience. In doing so, it grapples with the contribution of both psychological and social constructionist perspectives when endeavouring to understand the function and performance of the narrative. The latter sections of the chapter include: an overview of the ethical challenges presented by the work, a consideration of the intricacies of the process of research production, and a synopsis of analytical matters. I finish with an introduction to the seven research participants, who have unreservedly and collaboratively provided the material needed to make this thesis possible.

It is worth pointing out here that, although there are seven distinct sections to this chapter, issues related to ethics and analysis will also appear and be discussed in other parts of the text. Additionally, the findings of this research project will be incorporated into the individual thesis' chapters, including, to a lesser degree, this methodology chapter. This is as opposed to appearing as a distinct chapter by itself. The findings are embodied in the views expressed by the participants, and will be subsequently evaluated within the supporting/opposing theoretical literature.

a. Narratives of disability theory

The philosophical underpinning of this methodological approach is located in social model disability discourse; a social constructionist paradigm which emerged in the UK in the 1970's reflecting a growing transformation in disabled people's understanding of their position in society (Campbell and Oliver, 1996). The social model, in its most essential form, defines disability as a process of oppression that excludes those with impairments from mainstream social activities. Critical to that definition is an understanding of the distinction made between disability and impairment. Whilst impairment relates to the individually based biophysical condition, disability is about disabled people's exclusion (both physically and socially) from society (Barnes, 1996). The social model stands in opposition to the hegemonic medical/individual model of disability, with its focus on physiology and the achievement of an ill-perceived "normality."

The social model perspective has been a liberating force in many disabled people's lives, both at an individual level, when endeavouring to understand disabled people's own disability-related conflicts (Tregaskis, 2002), and collectively, when galvanising groups of disabled people to achieve an intended goal. As Chloe comments about her involvement in the disabled people's movement:

".....there was no space for me in the world; there was nothing for me to do with my skills. There are things that I thought were bad points, that I now know are skills, things that you reclaim as a disabled person. That's what disabled people are supposed to be doing. We fight back, we fucking fight back, and if it takes me the rest of my life then I'll do everything I can to keep fighting back."

Chloe (research participant, refer page 53)

In recent years, the complexities of arriving at an all-embracing, unequivocal definition of disability has become apparent. Although acknowledging that the social model has played an essential role in highlighting disabled people's oppression and challenging societal perceptions of impairment as a "personal tragedy" (Crow, 1996), it has increasingly come under attack. Criticisms

essentially relate to orthodox materialists' concentration on socio-economic dimensions of disability and their neglect of the cultural dimensions of the issue, including the individual's experience of gender, race, sexuality and impairment. Critics view this oversight as a denial of disabled people's subjective reality (Morris, 1992; Crow, 1996; Hughes and Paterson, 1997). Crow (1996), in particular, argues that the theorisation of impairment and the individual's experience of the body require more focussed attention. Along similar lines, Scarry (1985) believes that the embodiment of pain, for example, creates unique problems for theory by resisting language and articulation.

The partitioning off of disability and impairment by orthodox materialists has led to authors, such as Shakespeare and Watson (2001), advocating an abandonment of the social model, seeing it as having "outlived its usefulness." In opposition to this viewpoint, and in fear of losing the political urgency embodied in the social model, Thomas (2004) calls for the reclaiming of the social relational qualities of theorisation contained in the early writings of Finkelstein and Hunt. By revisiting this perspective, Thomas believes that it is possible to acknowledge that impairment is the fundamental starting position from which a conceptualisation of disability has been possible. This perspective, she argues, permits an acknowledgement that "impairment and chronic illness directly cause some restrictions of activity" and that "such non-socially imposed restrictions of activity do not constitute disability."

In terms of the everyday lives of disabled people, and with some impatience, Oliver (2004) has made the point that too much time has been spent debating definitions of the social model within the academy. As described by Chloe, the social model needs to remain as a practical tool to produce social and political change.

By employing narrative methodology and focusing on individual experience, I have worked with an extended version of the social model, which offers other dimensions to disabled people's oppression. In that sense, Barnes (2003) would describe my approach as that of a "rectifier." It both acknowledges socio-economic factors in disabled people's oppression, and concerns itself

with the impaired body and its relationship with prejudice. This prejudice is illustrated in society's cultural representations of disability (Chapter One, pages 15-17). It can also predominate disabled and non-disabled people's interpersonal relationships, contributing to disabled people's objectification (Shakespeare, 1997); a process referred to as "othering" in feminist literature (Wilkinson and Kitzinger, 1996). As already described, this prejudice potentially impacts on disabled people's self-esteem (Chapter One, page 16), so contributing to an internalised oppression, which may be both consciously and unconsciously held (Marks, 1999). These disabling cultural beliefs have impacted upon all research participants' lives in a number of ways and have played a significant role in differing aspects of their abuse experience.

The definition of disability that has had the most relevance to this research project, therefore, is Thomas's social relational definition of disability (1999):

"Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being."

Thomas (1999, page 60)

The effect of investigating the sexual abuse of disabled children using a social model perspective has been to resist the location of causality within the individual's own impairment. The issue, instead, requires evaluation in terms of a societal context of denial and indifference rooted in the generalised devaluation of disabled people's lives (Calderbank, 2000). This, in turn, plays a significant role in creating discriminatory social structures, which segregate, de-personalise, and reinforce otherness, placing disabled children in situations of unacceptable risk (Curry, Hassounah-Phillips and Johnston-Silverberg, 2001). Sobsey (1994) offers a useful "ecological model," which attempts to analyse the complex and unacceptable position that disabled children are placed in. The model describes the interaction between, firstly and most significantly, the socio-cultural context of disability, secondly, the individual's own situation, which usually includes the failure of health and

social care agencies to adequately address the needs of disabled people, and lastly, the characteristics of the offender.

b. Narratives of disability research

Another implication of approaching this area of work from a social model perspective has been the commitment to applying emancipatory research principles, which Barnes describes below:

“In contrast to traditional investigative approaches, the emancipatory disability research agenda warrants the generation and production of meaningful and accessible knowledge about the various structures – economic, political, cultural and environmental – that create and sustain the multiple deprivations encountered by the overwhelming majority of disabled people and their families.”

(Barnes 2003, page 6)

The emergence of the emancipatory disability research model resulted from growing criticism in the 1980s and early 1990s from a number of disability theorists and activists about fundamental aspects of traditional disability research. Based on what Oliver (1992) refers to as “methodological individualism” research, whether medical or social in nature, sought to analyse and quantify the individual’s experience of impairment, as opposed to deconstructing the social and cultural elements that contribute to disabled people’s common experience of oppression. The research process was viewed as being built on non-reciprocal and exploitative relationships, which were largely self-servicing, failed to examine the power dynamics inherent within and alienated disabled people even further (Hunt, 1981).

The reconceptualisation of the meaning of disability, and the growing dissatisfaction with key elements of disability research production, culminated in a series of seminars held by the Joseph Rowntree Foundation in 1991. These seminars provided a forum for the development of the emancipatory disability research model (Barnes, 2001). Taken from a paper written with Emma Stone (Stone and Priestley 1996), Priestley (1997) cites six core

principles, which he feels typify emancipatory research, and which were guiding principles in this study. These principles include:

- The adoption of a social model of disability as the ontological and epistemological basis for research production.
- The surrender of falsely-premised claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation.
- The willingness to only undertake research where it will be of some practical benefit to the self empowerment of disabled people and /or the removal of disabling barriers.
- The devolution of control over research production to ensure full accountability to disabled people and their organisations.
- The ability to give voice to the personal whilst endeavouring to collectivise the commonality of disabling experiences and barriers.
- The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

Emancipatory disability research ideals have generated much debate within academic circles for more than a decade. Materialists, such as Oliver (1996), write about the process of research production and questions the achievability of empowerment implied within the research paradigm. He states that empowerment can only be defined as such after the event and any attempt to “do” emancipatory research constitutes a flawed starting position. He believes that research can only assist those seeking to empower themselves and, in that respect, researchers need to be more concerned with whether or not they played a useful role in the process or, in fact, contributed to a process of disempowerment. He adopts a self-defacing stance in relation to his own involvement in past research projects and asserts that unless the social and material relations of research change, with disabled people having full control of resources and the research agenda, then research can only

ever be participatory, with researchers being the main beneficiaries (Oliver, 1999). Oliver also questions the emancipatory value of research, such as mine, that focuses on the individual experience of impairment.

In a similar vein, Barnes (2003) investigates some of the key aspects of the emancipatory research ideal and also problematises their achievability. Unlike Oliver, however, Barnes is less cynical about the process of empowerment. He feels that, because of economic forces, there has been a shift away from social researchers controlling the research process. Although agreeing that empowerment is something that disabled people do for themselves, he does believe that research findings stimulate and reinforce the demand for change and, in that sense, have an important role to play in the process of empowerment. Barnes, like Oliver, questions the emancipatory value of research exploring personal experience, a position refuted by a number of feminist writers (French, 1993; Crow, 1996; Marks, 1999), myself included. My personal view is that, by focusing on the individual experience, it is possible to draw out the social and cultural influences that contribute to the political circumstances surrounding disabled people's oppression. In fact, it was the sharing of the individual experience of impairment in the early stages of the development of the disabled people's movement that generated the collective of the social model in the first instance (Oliver, 2004).

Emancipatory disability research, which this piece of work strives towards, owes much to other academic disciplines, particularly feminism. Of significance are the writings of authors such as Stanley and Wise (1983) who criticised mainstream (malestream) research in the social sciences as objectifying and alienating women. Stanley (1990) writes about the male dominated academic mode of research production, where female students and teaching staff have been concentrated in particular subjects and at lower levels of academic hierarchies. Additionally, "research subjects" have been disproportionately female, yet male experience forms the "norm" against which research findings are evaluated. Clearly, parallels can be drawn for disabled people's involvement in academia, whether as employees or the

researched subjects, complicated even further by issues of race and sexuality.

The process of repositioning the subject is common to both disciplines. In early feminist writings the means of dealing with women's exclusion in mainstream social theory was largely additive, with women's experiences being drawn upon to correct unbalanced arguments (Smith, 1987). This is also similar to the way in which disability is often tagged on to lists of sections of society that also experience oppression. The emergence of "standpoint" theorising within feminism relocated women to the centre stage and analysed, and continues to analyse, the world from where women stand (Irigaray, 1993). This, in a sense, is analogous to activities within Disability Studies and the disabled people's movement. Here, issues are now being critiqued from disabled people's perspectives, with an accompanying modification of language where disability denotes the "norm" from which non-disabled people are categorised as other (Swain and French, 2000).

Feminism was also one of the first disciplines to meaningfully examine the power dynamic inherent in the research relationship. It challenged the traditional dualistic research model that consisted of the impartial and objective researcher and the research subject. Stanley and Wise (1990), when talking about feminist epistemology, believe that it is impossible for researchers to approach their work with, what they would describe as, "an empty head" with theory being unaffected by their own life experiences. They believe that feminism should be present in positive ways within the research process, as principles underpinning behaviour, in the same way that the social model of disability should underpin emancipatory disability research ideals. Feminist epistemology has made no attempt to sanitise the process of research production, arguing that the development of a research relationship, with the consequent exchange of ideas and feelings, is necessary for the emergence of data (Greed, 1990).

One of the major contributions of feminism has been to validate the experience of ordinary women by espousing the notion of "the personal as

political.” But here lies the “rub” for disabled feminists. Despite acknowledging the substantial contribution that feminist theory has made in deconstructing the source of disabled people’s oppression (Morris, 1996), there is still a feeling that feminism has rendered disabled women’s experience largely invisible. One of the most classically cited examples of this omission centres on feminists’ concerns about the exploitation of unpaid female carers undertaking care in the community for elderly and disabled people. Here, the gendered division of caring was problematised, yet the polarisation of female carers and those who require care was left unanalysed (Dalley, 1988). There was neglect of the fact that women (elderly or impaired) were both being cared for, as well as caring for others (Morris, 1993). Such objectifying research only contributes to a process of alienating disabled women further.

In the 1970s and 1980s black feminists criticised mainstream (white, middle-class) feminism for failing to theorise the interconnected and enmeshed relationship of race and gender (Bhavnani, 1997), thus perpetuating an objectification and dehumanisation of black women (Hill Collins, 1990). Today, disabled feminists criticise feminism for polarising disability and gender in the same way (Thomas, 1999).

In relation to this research, one of the main objectives is to give voice to the experience of disabled women and men who have been sexually abused in childhood and then, as Priestley (1996) writes, “collectivise the commonality of their experience.” In the same way that Maynard (2000) stresses the importance of theorising the inter-relationship between race and gender in black women’s oppression, data analysis has looked at the interlocking systems of oppression that contributed to participant’s sexual abuse as children.

c. Narratives of method

In terms of methodology, the subject area was investigated using narrative methodology. This particular approach has re-emerged in the last twenty years, in sociology and other disciplines that study human behaviour, as an effective means of data collection (Maine, 1993), which has the potential to generate rich and complex data. This trend in academic circles accompanies, what Plummer (2001) describes as, the emergence, generally, in the twenty-first century of an “autobiographical society” with a notable shift away from oral traditions of story telling towards the telling of lives inscribed in written text.

Denzin (1989) draws distinctions between the differing types of biographical forms that can be used for research purposes. Although the distinctions between these different categorisations are subtle, Denzin would classify the narratives produced within the context of this particular research project as “personal experience narrative.” Here, the narrator describes a set of events that exist independent of their telling. The focus lies in the shareable experience, and meaning is drawn from a common understanding that unites the researcher and the participant. Additionally, this understanding has the ability to create an emotional connection between the listener and the storyteller. As an antithesis to the traditional qualitative structured interview where the agenda is predetermined by the researcher, within this type of research the development of the narrative rests on what the interviewee feels able to share and, in that sense, is less predictable in terms of content. The responsibility of the researcher is to be a good listener who is committed to listening attentively and respectfully and who might probe and draw out themes from the narrative. The role of the interviewee is that of an active storyteller rather than a respondent (Hollway and Jefferson, 2001).

The appropriateness of the methodology, lies in a belief in the inseparability of the narrative, the act of telling one’s life story, and the self (McAdams, 1993). In fact Clandinin and Connelly (1994) write “we live out our story through our

experience, tell stories of those experiences and then modify them through retelling them.” This perspective, therefore, sees narratives as a tool for mediating our understanding of ourselves, and navigating our relationships with others (Ochs and Capps, 1996). In that sense, narratives are believed to be fundamental to our identity formation (Swain and Gillman, 2000).

Bruner (1987) goes one step further in his thinking about the function of narrative as identity. He hypothesises that storytelling, and the methods of conceptualisation embedded within it, become so ingrained that they become recipes for structuring experience itself and directing it into the future. This viewpoint stands in opposition to those who argue that narrative formulation cannot be consciously lived out in practice, since life is too unpredictable and stories can only ever be told after the event (Crossley, 2000).

Of particular relevance to this project is Linde’s (1993) reference to an individual’s need to produce coherent narratives of self, which help to sustain personal integrity. This process becomes most apparent, she believes, when unexpected life events suspend the individual’s ability to produce a coherent narrative, so creating confusion and unease until the new event can be successfully accommodated into the individual’s ongoing story. This process could clearly be seen in participant’s inability, in childhood, to understand and integrate their abuse experience (Chapter Five, page 212). It could also be seen in their later struggles, as described in Chapter Six, to produce more reflective and empowering narrative accounts. Cohler’s work (1991), which reflects on the wider role that trauma plays in the construction of a narrative, also bears some relevance to this thesis. Cohler contends that trauma forms a point of reference around which subsequent “good” stories are told. I would assume that Cohler’s description applies to the listener perspective and, certainly, for one participant in this study, there was some reference to the entertainment value that their narrative subsequently provided for others.

The psychological perspectives of such writers as McAdams (1993) have also provided a useful point of reference in terms of justification for researching the stories of disabled adult survivors of childhood sexual abuse, as opposed to

children. Apart from ethical concerns, such as the possible negative psychological effect of a young person's involvement in life story research, there is also some questionability relating to a child's cognitive capacity to narrate a story of self. McAdams contends that it is not until late adolescence or early adulthood that individuals, with the help of social networks and educational opportunities, are able to begin the process of constructing frameworks for understanding themselves and the world, so facilitating the formulation and reformulation of identity and the ability to story one's life.

An over-emphasis on the psychological function of narrative, a perspective which generally sees narratives as being independent of the context of their recounting, runs the risk, in the eyes of some writers, of negating the discursive production of the social self (Atkinson, 1997). Even authors that hold fundamental beliefs in the psychological function of meaning-making embodied within the narrative, recognise that the relationship between lived life and life story, as told in the context of the research interview, is far from simple.

Social constructionist enquiry, which focuses on questions of how knowledge is produced, has also been of relevance to this research approach. Social constructionism is critical of positivist and empiricist stances that propose artificial categorisations, and insist that people construct knowledge between themselves through their social interactions and within a historical and cultural context (Burr, 2003). A social constructionist approach to narrative would stress the temporality of narrative and the fact that they are in a constant state of flux. It proposes that narrative is continually being deconstructed and reconstructed depending on the period of time, the mood of the narrator and the audience in question. Mischler (1991) writes about the joint construction of meaning between the interviewer and interviewee within the interview context, believing that processes of reciprocity and re-evaluation determine the end product. He contends that any interview takes the form of a circular process through which meaning is constantly refined as both parties attempt to make sense of what each other are saying. I would contend that, for storytellers, it is through this process of circularity that they determine the safety of the

research environment. For social constructionists, variation across a number of interviews is not viewed as a technical error requiring analysis of how a question is asked, for example, but rather significant data for analysis.

Freedman and Combs (1996) cite four notions related to a social constructionist/postmodernist view of narratives:

- Realities are social constructs.
- Realities are constructed through language.
- Realities are organised and maintained through narrative.
- There are no essential truths.

They also write that in narrative research enquiry, it is more important to “approach research participants and their issues with attitudes supported by these ideas than it is to use any particular narrative technique.” According to Reavey (2003), when applying a postmodernist perspective to narratives of childhood sexual abuse, the experience of child sexual abuse is not seen as a “fixed ‘truth’” that the researcher should be preoccupied with investigating. Sexual abuse discourse is seen, by contrast, as a phenomenon constructed in a historically and gendered context and reproduced in its telling.

Research, such as mine, that uses narrative methodology stands in opposition to the fluidity implied in overly postmodernist perspectives (Goodley, 2001). Whilst acknowledging that narratives are not transparent phenomena, which contain absolute truths, I believe they do stay close to actual life events. They contain some concrete factual information of which participants have spent significant periods of their lives trying to make sense of (Bauer, 1996).

Crossley (2000), when examining the emergence of postmodernist thinking within feminist psychology, writes about its initial positive contribution to the necessary highlighting of the individual’s social context of oppression. However the continued concentration on the linguistic and social construction

of the “self”, Crossley believes, has detracted from the important task of exploring the individual experience in some depth. She argues that this has perpetuated a “losing of the subject.”

Similarly, Oliver (2001), whilst weighing up the potential positives and negatives of the emergence of a postmodern society for disabled people, voices concern about the postmodern nature of theorising. For academics, again, he believes the goal of objectivity is dismantled, thus creating a situation whereby the analysis of all aspects of the experience is compromised. For activists, it is seen as irrelevant to most disabled people’s lives. Other disability writers however, such as Corker (1998), feel that dismissing postmodernist perspectives in Disability Studies is unhelpful. She contends that a postmodernist perspective lies at the very heart of current criticism of the essentialist nature of orthodox definitions of the social model. A focus on the social, cultural and linguistic construction of disability, she believes, is more in line with poststructuralist theorising. She argues that postmodern discourse, does not reject the social model of disability, it just broadens it.

The use of narrative methodology to explore the lives of disabled people has been a relatively recent development. Some research has focussed on disability and identity, illustrating the negative impact of living in a disabling society (French and Swain, 2000). Others have highlighted some of the positive implications of impairment, such as being able to opt out of a non-disabled “competitive” lifestyle (Shakespeare, 1996b). The absence of disabled people’s voices in narrative research has been most noticeable in relation to people with learning difficulties, which Walmsley and Atkinson (2000) believe relates to their historical legacy of devaluation. Narrative enquiry with this group, until several years ago, concentrated mainly on the perspectives of parents and carers (Goodley, 2000) and was based on the assumption that people with learning difficulties were unable to articulate their experiences (Booth and Booth, 1994). However, the situation is now beginning to change, a move that Walmsley (2001) attributes to the change in ideology driven by the social model of disability. She also makes linkage with

the modification of funding arrangements, where research applicants are expected to actively involve people with learning difficulties in their research.

For this particular piece of work, narrative methodology was felt to be totally appropriate as a means of understanding the experiences of subjects at the level of feeling as well as meaning (Booth and Booth, 1997). In particular, it provided the opportunity to gain insights into the way in which disability and child sexual abuse interacted, so affecting identity formation and narrative construction. The subjective narrative, which used the words of the participants, was felt to provide all the ingredients to allow myself, as a researcher, to understand a life from an insider's point of view (Atkinson, 1998). The work will contribute to a growing literature written by disabled people about the lives and perspectives of other disabled people, celebrating their strengths and resilience and challenging the negative stereotypes (Swain and Gillman, 2000). In doing so, it will expose the oppressive social structures which have contributed to the silencing of disabled survivors' voices.

d. Narratives of ethics

“ Ethics relates to the moral value of human conduct and the rules and principles that ought to govern it.”

The Collins English Dictionary, 1986

I have placed this quote at the beginning of this section, reflecting the necessary predominance that ethical evaluation has played in this study. Ethical scrutiny, according to Truman (2003), has become a high profile concern of academic institutions undertaking work in the field of health and social care. Research committees place emphasis on “the protection of vulnerable research participants” and the provision of guidelines for research practitioners, but have little regard for the everyday ethical dilemmas of fieldwork practice. Truman contends that, in reality, two ethical worlds exist, one preoccupied with the machinations of ethical research committees, and the other concerned with the subjectivities of the research process. Whilst

acknowledging the importance of some form of ethical governance, it is with regard to these subjectivities that this section of the chapter is concerned.

On a personal level, ethical evaluation has played a role in determining the appropriateness of this research topic, in the first instance. It is consistent with a political ideal that demands equality and which creates obligations, such as a responsibility to promote the active involvement of participants in the production of an accurate narrative account of the self. It has brought about a necessity to make apparent the causative relationship between any participant's personal difficulty and the larger social context of oppression. Invariably, it has applied to decisions relating to the ongoing management of the research relationship.

Swain, Hyman and Gillman (1998) believe that the question of ethics needs to be "constructed and confronted" throughout the research process, from submission of the initial research proposal, to final publication. Accordingly, they offer a number of ethical guidelines, which they feel need consideration. They write that the lived experience of the participant cannot be divorced from the actions of the researcher and, in that sense, researchers have the responsibility to negotiate difficulties relating to the research context as they arise. They also believe that the greater the control the participant has in the process, the less likely the research is to infringe their rights. Implicit in these guidelines is a commitment to sustain an open and honest partnership. As Punch (1998) writes, any attempt to dupe participants in action (emancipatory) research would be to undermine the very processes one wants to examine. These general principles of openness, respect for the participant and respect for the participant's autonomy are consistent with French's description (2004) of the deontological model of ethical decision-making.

Newman et al. (1997) contends that the most frequently debated ethical concern relating to trauma-based research focuses on the potential for re-traumatisation of participants through their involvement in the process, possibly creating unwanted reactions, such as flashbacks or suicidal ideation.

Brzuzy et al. (1997) also raise such concerns in their own work, reporting that in a number of cases, participants did in fact describe negative consequences. These symptoms included anxiety in anticipating the interview and nightmares after the event. Brzuzy et al. offer a number of guidelines that assist in preparing participants for the interview experience and which also provide a level of support once the interview has been completed. All these considerations have been informative in this research and some, where relevant, have been put into practice.

The general lack of empirical research on the psychological risk of involvement in trauma-related research prompted Newman (1999) to study the ethical costs and benefits of participation. Using a large cohort, adequate preparation and a combination of questionnaire and interview methodology, she concluded that the majority of participants reported benefits from their involvement. The small minority of those who did report a degree of distress believed that it was tolerable and didn't prevent continuation. Disch's study (2001), which looked specifically at research with survivors of sexual abuse perpetrated by professionals, supported Newman's findings. She found that when participants were fully informed about the research and participated through their own free will, they were able to handle the feelings that the research generated and, in fact, were able to use these feelings to further their own personal healing process. Research such as this provides the ethical validation for embarking on such a sensitive area of research. It also provides reassurance that involvement is likely to be of differential value to potential participants, and that this supposition is not, as Bar-on (1996) writes, an illusionary, self-serving bias.

Castor-Lewis (1988) discusses a range of other ethical issues that relate to research involving survivors of incest, all of which have been pertinent to this piece of research. A major consideration, Castor-Lewis argues, is the need for participants to have a support system in place before embarking upon the research process or, at the very least, a list of agencies who could offer counselling. This would be someone who could pick up on the difficult emotions triggered by the interview process. Similar to the work of Herman

and Hirschman (1981), a precondition of participation in this research was the existence of an adequate and verifiable support system. This provided some reassurance that participants would not have to deal with difficult emotions alone. It also meant that, by knowing that the participants had previously shared the experience with others, the possibility of receiving fresh disclosures would be reduced, which, as a lone researcher, I did not have adequate resources to manage. This would particularly be the case if disclosure involved immediate issues of safety relating to children currently in contact with the perpetrator (Swain, Heyman and Gillman, 1998).

Castor-Lewis (1988) also advises on the need for researcher support and the value of having a colleague to share feelings generated by the overwhelming affective nature of the material. Brzuzy et al. (1997) support this view and also offers other guidelines related to interviewer de-briefing, including the usefulness of researchers recording their initial response to their involvement in the process. As well as providing a helpful medium of expression, they believe that this can create emotional insights into the ongoing research process. To be of value, however, Thompson (1995) cautions on the need for this to be done immediately after the interview, since the same psychological dynamics of dealing with trauma for the victim (blocking, minimising, forgetting) can also be mirrored in the researcher's own process. This method of note taking was adopted in this research and was found particularly helpful when reflecting upon and understanding interview dynamics, especially the influence of my own comments on the process. Note taking also assisted in the analysis of the structural qualities of the narrative production. It included such considerations as: why the story-teller developed their story in a certain way, what were the power relations inherent within the encounter and what was taken for granted by the storyteller and listener that assisted in making sense of the discourse (Kohler Riessman, 1993). In relation to the latter point, for example, it included a shared belief in the potential for destruction that child sexual abuse creates in the lives of survivors. It also included an expectation that I would be familiar with most aspects of the topic under discussion and would be able to deal with the emotion generated by the story.

e. The narrative of the narrative production

The sample for this study was acquired through a process of self-selection, with potential participants replying to advertisements placed in several national disability magazines and the websites and newsletters of various national and regional disability organisations. This was in line with research findings, such as those of Disch (2001), that highlight the importance of participants being able to freely volunteer themselves for involvement in the research process. The advertisement appeared both as a box advertisement (**Appendix A**) and as an article that concluded with details of the research (**Appendix B**). Although it was acknowledged that this recruitment method would probably not be a representative cross-section of the disabled population, this bias was felt preferable to the bias incurred when using other methods (Booth and Booth, 1997). Advertising over a period of months, using the methods described, produced eight suitable volunteers, one who later withdrew because of her possible involvement in a non-related but relevant court case.

The final sample was spread across the socio-economic/class system, with five of these seven participants originating from working class backgrounds. Two participants identified as lesbian, one as bi-sexual and four self-identified as heterosexual. Five participants were female and two were male. Most were white British, with one participant being of Anglo-Asian ethnic origin and three having been born outside the UK. With the exception of one participant who currently lives in Europe, the sample was evenly spread across the UK in terms of their current place of residence. Their ages ranged from mid-twenties to mid-fifties.

Because of well documented evidence that children with learning difficulties are particularly at risk of sexual abuse (Sobsey and Doe, 1991; Sullivan et al., 2000), and also because of criticism from within the disabled people's movement relating to the marginalisation of people with learning difficulties (Walmsley 2001), it was felt imperative to gain access to this group of

individuals. Consequently, a nine-month period was spent working with a local People First organisation preparing an accessible article for one of their regular magazines (**Appendix C**). Although the work did not produce any volunteers, it did act as a catalyst for the generation of narrative accounts of member's involvement in both physically and sexually oppressive relationships. This was often with other adults with learning difficulties, a fact that is supported by other writer's work in this field (Brown, Stein and Turk, 1995). Further exploration of this area is worthy of a thesis in itself.

The process of consenting to be involved in any research, but particularly research that involves previous sexual trauma, offers a number of other ethical issues for consideration. Newman et al. (1997) writes that, because of issues relating to self-determination, gaining informed consent "fulfils the researcher's obligation to provide a fair, respectful and clear agreement between the researcher and the researched." Getting to the point of obtaining informed consent is seen by Fryer (1995) to be related to the quality of information received by potential participants and the way that the information is perceived and understood.

In this study, some general information was given regarding the objectives of the research, the potential methods of narration and expectations of participation. It also included a brief description of myself, and details of my professional background (**Appendix D**). Additionally, I provided some basic information relating to the ethical guidelines that governed the interview process (**Appendix E**), including factors such as consent, confidentiality and control within the interview situation.

Explaining one's research, Walmsley (1993) contends, requires consideration of how detailed the description of the research is, how much personal information the researcher gives of themselves and whether potential participants might identify as belonging to an oppressed and stigmatised group in the first instance. As already alluded to in a previous section of this chapter (page 33), Walmsley stresses the interactive nature of this part of the process. Explanations generate feedback, which can then warrant

adjustments and give the researcher more information about the participant's world.

Lee (1993) cautions on the potential difficulties of defining the research topic too tightly in these early stages, contending that this may preclude the respondent from defining it in their own way, so preventing them from raising other topics. Additionally, Murray et al. (1979) advises on the appropriate time to seek consent. He believes that the obtaining of informed consent in research that deals with sensitive and confidential matters is only possible once trust has been established within the research relationship. He argues that where this has been done properly, consent becomes implicit. Retrospectively, I can see that for one participant in this study I had not paid enough attention to establishing a relationship before asking for consent. This manifested itself in an uncertainty about signing the consent form (**Appendix F**) until later on in the process. Sin (2005) argues that, in reality, consent seeking is not a single event and that "different types and levels of consent are required before, during and after the act of research" with the latter raising consent issues relevant to publication.

The sharing of personal information at this stage of the process also offers its own dilemmas. Of relevance here are the writings of Cotterill and Letherby (1993) who assert that researchers need to give careful consideration to their own experience and then locate themselves in relation to the subject under investigation. In this particular study, the early sharing of autobiographical detail considered to be largely unproblematic did, I believe, effect how freely one participant was able to verbalise their opinions on how disabled children can be problematically perceived by their parents. This dynamic highlighted one particular source of contradiction for researchers working as "insiders." Whilst there was a shared identity of belonging to an oppressed section of society, at the same time I represented a potential oppressor (Thompson, 2003). The reality of this situation reflected the fact that, when researching the experiences of oppression, there is no neutral ground for the researcher (Vernon, 1997).

Examination of the role that reciprocity plays in facilitating a positive research relationship, with the ultimate production of a “good” narrative, has only relatively recently been opened up for discussion within feminism. Oakley (1981) was perhaps one of the first feminist writers to challenge the traditional male objectifying research model. The model made a presupposition that research should be a one-way process, with the researcher being the recipient of information, resisting any desire to share personal thoughts, feelings and experiences. One of Oakley’s more poignant points, relevant to this study, was her questioning of a researcher’s refusal to offer some personal involvement in the process when engaging in research which expects its participants to share intensely personal information.

In a similar vein, Ribbens (1989) argues that there are various levels of reciprocity that apply to the qualitative research process. The first concerns how the researcher responds to direct questions from the interviewee. The second concerns the issue of self-disclosure and whether the researcher should take the same risks that they ask the interviewee to take. She raises the issue of researchers possibly taking a more active role in volunteering information, despite running the risk of interrupting narrative flow and being seen as a hindrance to the process. I believe this to have been the case in one of my own verbal interjections with one particular participant. Here the offering was made with good intention but, instead, took the focus of attention away from the participant, albeit temporarily. Patai (1988), with this in mind, cautions on the negative consequences of locating the self too centrally in the inquiry, thus perpetuating the dominance that emancipatory research, in this case, hopes to counter. In relation to reciprocity, Ribbens (1989) concludes that researchers should take their cues from the person being interviewed, and that the stage at which a researcher inputs is partly determined by the type of end result that is being sought.

Stanley (1991), when talking generally about the process of reflexivity within the autobiographical research process, espouses the value of opening up the research process, including the interview dynamics, for scrutiny. She argues that reflexivity, informed by social constructionist ideals, can play a positive

role in the production and analysis of the autobiography. In this research, one participant illustrates this point well when reflecting upon the process of narrative production. She comments that her narrative would have unfolded differently had she been telling her story independently. This point illustrates the interactive nature of the process and validates Stanley's assertion that autobiography cannot be divorced from biography.

Guidelines relating to the nuts and bolts of conducting life story interviews have been provided by a number of authors, covering a range of topics including interview approaches and styles, tape recording, location of interview, etc (Miller, 2000b; Atkinson, 1998). Atkinson (1998) argues that having got to the point of agreeing to be involved in the research, participants are generally eager to tell their story but will often need to prepare and organise their thoughts beforehand. The participants in this study were told before the interview that I would be asking them a generative narrative question (Flick, 1998), which took the form of: "could you tell me the story of your life with reference to the experience of child sexual abuse and, also, more general happenings of significance." They were also given sight of the following additional questions, which would have been addressed had these issues not been covered within their narrative:

- What factors, do you believe, put you at risk of child sexual abuse?
- What are your thoughts on why perpetrators commit such offences?
- How has sexual abuse affected your life and do you believe that non-disabled people would identify the same types of problems?
- What strategies have you used to survive the experience?

Bearing in mind each individual's differential ability to tell a "good" story, the idea of a timeline (Walmsley 1998) was introduced to participants, which involved breaking down the life story into episodes, so facilitating a more

manageable presentation of material. This approach is consistent with the writings of Flick (1998) who argues that individual experiences are remembered in the form of both narrative-episodic knowledge and semantic knowledge. Whereas episodic knowledge is linked to concrete situations or events, semantic knowledge relates to the meaning abstracted from those events. Rosenthal (1993) believes that the process of selecting which episodes to share in the interview is not an arbitrary one for the participant. He asserts that choices are made relevant to both the constantly shifting biographical structure of meaning attached to the narrative, and the interview context itself. The narrated story, he argues, consists of a sequence of mutually interrelated themes derived from this continual meaning-making process, an issue that will be given further consideration in Chapter Six.

Consistent with Och and Capp (1996), who feel that narrative performance can take many forms, a number of methods of narration were suggested to the participants, including a combination of approaches. In the end, Lizzie, Lyn and Josh told their story during a face-to-face interview. Thomas chose a combination of methods including interview, written material (story and poetry) and photography. Chloe opted for interview and later supplied poetry. Jean decided on an interview accompanied by story and artwork, and May produced an autobiographical account relayed via e-mail. All of the participant's written material and artwork were given freely with the intention of its incorporation into the research project, and a selection of it can be seen in **Appendix G**.

Increasingly, qualitative research using the internet is becoming recognised as a valuable method of data collection, particularly for hard-to-reach groups (Brownlow and O'Dell, 2002). Mann and Stewart (2000) write that internet research can provide anonymity for participants, where the visual social cues that can inform power relations are eliminated. For women, generally, they believe it has become one of the safest places to communicate and, similarly, for disabled people it has also provided a level of accessibility, facilitating participation in an alternative way. Mann and Stewart acknowledge that there is an uncertainty relating to whether email can be used effectively for

researching intimate subject matter (a question, they believe, that needs to be answered by further research). In this research, although it seemed to be effective as a means of collecting a life story and provided the necessary distance and safety required for one participant, certain aspects of the process I found to be problematic. This mainly included the lack of non-verbal information indicating how the process was being experienced at the other end of the line.

In face-to-face interviews dealing with subject matter such as mine, reflexivity, I believe, becomes an ever more crucial component of the interview process. Castor-Lewis (1988) contends that when interviewing survivors of sexual abuse, particular attention needs to be paid to power differentials and any perceived threat of boundary invasion, which could mimic the dynamics of the abuse. She writes that participants need to be given a sense of control, with permission given to stop the interview at any time, and them feeling that they have the freedom to be selective about what they choose to share. Different participants in this research project exercised one or both of these rights. Thompson (1995) asserts that sensitivity to the pace set by participants when telling their story is vital. She argues that body language provides the necessary information to determine when it is appropriate to move on and whether it is acceptable to return to enquire further about certain episodes. She believes that maintaining good eye contact is particularly important and that the process is often hindered when researchers refer back to their notes, as was the case on one occasion with one of my participants.

The question of what drives participants to generously offer up their life story for interrogation in such a sensitive area of research perhaps requires some further consideration. Disch (2001) has been one of the few researchers to incorporate this aspect of the research process into her analysis. She collected data from survivors that identified beneficial consequences ranging from increased self-awareness and empowerment, to feelings of validation and lessening of the sense of isolation. A desire to help other survivors and educate professionals were also often motivating factors. Although this type of information was not systematically collected in this research, the participants,

at various stages of the process, offered views on this issue and below Lyn's quote provides one such example:

"Being involved in research is an experiment for me in that I haven't had this sort of conversation in a non-therapeutic context before except with my partner. Talking about it to an almost stranger is different, but I do feel that the reason that I have gone through all of this in the past couple of years has been to sort out my life and try to be happier."

Lyn (research participant, refer page 52)

Other benefits cited by the participants in this study included: being able to use the narrative to supplement other methods of exploring the life story (Jean), being able to experience the story as a whole, rather than the fragmented bits worked upon in therapy (May), showing parts of the transcript to friends in order to explain certain factors too difficult to verbalise (Lyn), sending the narrative to an estranged (non sexually abusive) father, in order for him to understand her experiences (Jean). Below, Jean elaborates further on one of these points:

"The final thing I wanted to say is that my process of recovery has been about looking at the story of my life, so it's something that I'm continually working with in a therapeutic way and in my visual arts work. It feels good to be reflective about my past, to be able to see it all in context."

Jean (research participant, refer page 53)

This issue will be considered in more detail in Chapter Six when discussing the issue of narrative reconstruction. For all narrators, their participation was also motivated by a political need to contribute to a process of increasing public awareness of a neglected issue. It has also, undoubtedly, contributed to their process of creating a more positive narrative, reflecting an increased understanding of events and producing what Widdershoven (1993) refers to as an "edifying dialogue."

f. The narrative of the analysis

Following interview, all tape-recorded interviews were transcribed in full, incorporating most of the transcription conventions advocated by Miller (2000b). Kohler Riessman (1993) warns against the temptations of taking short cuts with this stage of the process, believing that perceived irrelevances in the transcript can often provide the contextual grounding for future interpretations. In that respect, Kohler Riesman would identify transcribing as the start of the analytical process.

After reading the transcript the participants were then invited to make any additions or omissions felt necessary, and once approved by the participants the transcripts were then turned into narrative form. Using a model adopted by Goodley (2000), when researching self-advocacy in the lives of people with learning difficulties, sections of the text were cut and pasted so that material was ordered more chronologically and achieved the fluidity more accordant with a story. This was sometimes at the expense of losing the potential to explore why, for instance, an episode of narration occurred at a particular point in the grand narrative. An example of this could be seen in the transcription of Chloe's narrative, where a significant period of time at the beginning of the interview was spent discussing her impairment. This reflected, I believe, the difficulty that a lack of diagnosis, and the associated misinterpretation of her behaviours, has played throughout her life. My comments and question that appeared in the transcript were omitted, as were repetitions, information not relevant to the story and the over use of regional expressions. My additions were made when it was necessary to connect two sections of discourse, alter grammar or aid the flow of the story. Very occasionally, my questions appeared in the narrative as if they were spoken by the narrator.

This uncomfortable part of the research process, where the participant's life story was placed in my editorial hands, highlighted the weight of responsibility incurred by the researcher at this stage in the process. Useful here are the

writings of Plummer (1983) who advocates that the task in hand, in this part of the procedure, is to produce good stories which do not lose their authentic meaning and which provide the foundations on which good theory can be based.

My editorial activities also lent credence to the work of Cotterill and Letherby (1993) who contend that researchers, through their involvement in the research process, actually become the participant's biographer. They argue that autobiographies are influenced by the research relationship, are interpreted using the researcher's own life experiences and, in that sense, researchers become the "filter" through which a participant's life is understood. For that reason, Punch (1998) calls for more researcher autobiographies in the final presentation of material, so adding another dimension to the work. Accordingly, my own autobiography appears at the beginning of this thesis. It stands alongside some of the self-composed descriptions of the participants appearing at the end of this chapter; so attempting an open analysis of the data which recognises the enmeshment of the researcher's own life history at every stage of the process.

Once a final version of the narrative was agreed to be acceptable to the narrator, further analysis ensued, which was in addition to the assessment of structural qualities of the interview detailed in section d, page 39, and the interview dynamics referred to throughout section e. Despite the growing literature on narrative research, Ollerenshaw and Creswell (2002) argue that the field of narrative analysis is still in its infancy, with differing disciplines concentrating on the analysis of different aspects of the text. The model of data analysis adopted for this project was the holistic content approach, abstracted from Lieblich et al.'s four-classification schema (1998), which works with themes emerging from the data. Because of the comparatively small-scale nature of the project, the processing of data using increasingly popular qualitative data analysis software such as Nud.ist or Atlas (Denscombe, 1998) was not even contemplated.

Instead, after repeated readings, each narrative was interrogated systematically by taking each paragraph separately and then categorising and developing its content in terms of ideas, events and mini-themes (Denscombe, 1998). Then, with the aim of abstracting meaning and social significance, the entire narrative was classified in terms of its emergent themes (Huberman and Miles, 1994). Interconnections between those themes and material that didn't fit into any category were also noted. One example of these interconnections was how, for several participants, the barriers to disclosure of abuse as a child interconnected with a disabling home environment where the child was perceived as a problem/burden.

Moving to a higher level of analysis, the further scrutiny of the themes resulted in the extraction of three over-arching and interlocking "grand themes" that cut across the data at a personal, interpersonal and societal level (Thompson, 2001). This also included a comparison of the material generated across all the participant's narrative and the production of a set of generalisations that added some explanatory weight to the themes. One such generalisation, for example, was the fact that the dissociative behaviour illustrated by all the participants in childhood was a legitimate and healthy mechanism for surviving the abuse experience and protecting the development of the "self."

A further re-reading of the narrative material was undertaken to ensure that the possibility of generating new themes had been exhausted. As Scott (1998) describes in her work with the survivors of ritualistic abuse, I had some difficulty, at this stage, in divorcing myself from prior experience, ideas, theories and ideology. Similar to the views of Mello (2002), I believe that findings do not emerge on their own in this stage of the analysis. They are partly attributable to the perceptions of the researcher and, in that sense, the abstracted meaning generated and developed from the data is as much a creative (but informed) process as it is an analytical one.

Clandinin and Connelly (2000) maintain that this part of the analysis exhibits a transformative quality. Here the field texts, which are characteristically descriptive and shaped around events, are turned into research texts. These

research texts take a reflective and distanced stance and are concerned, essentially, with meaning and significance. Having said that, however, for several participants in this study, their narrative account, as well as being descriptive and event focused, also contained elements of personal and social analysis.

It would be difficult to say that I adopted one particular mode of analysis. It is, perhaps, best described as a combination of approaches that considered both the influence of the research relationship and the emergent data. The approach was felt to be appropriate for managing and generating meaning from such rich and complex data. It was, to some degree, experimental. In retrospect, the initial stage of the process, which is categorised by some as “coding,” whilst undertaken because of personal anxiety related to the task of managing such lengthy narrative material without omitting, unwittingly, important information, was of limited value. It did provide a speedy referential method for retrieving material, but the breaking up of the data, in this way, interrupted narrative flow and provided little in terms of understanding the meaning embedded within the individual narratives.

The overall approach was consistent with the views of Mello (2002) who believes that, because narrative is ephemeral and personal in nature, it is necessary to attempt the application of multiple methods of understanding and investigating its production. He contends, and I would agree, that by examining narrative with reference to its differing basic constituents, and their relationship to each other, the method provides a contextually grounded approach from which it is possible to incorporate both researcher and researched meaning in the findings. As already indicated, my autobiography and viewpoint influenced the type of material generated within the interview context, i.e. the constructed management of meaning. As becomes apparent when reading the following chapters, it has also had some bearing on the pinpointing of particular issues for discussion (Rapley, 2001).

Three overarching and interlocking themes run through all seven narratives, namely: power, identity and narrative construction. These “grand” themes

comprise the substantive chapters in this thesis which, when subdivided, have created the necessary structure to incorporate the multitude of issues and perspectives raised by the participants. As the chapters have been produced, they too have been shared with the participants and comments invited. This process, however, has also been fraught with conflicting tensions, mainly centring round the function of the text and the differing requirements of the recipients of the material. For myself, there was a fear that the written text would destabilise the research relationship by positioning the material in a self-serving, reductionist format, with estranged ideology that did not speak to the participants (Clandinin and Connelly, 2000). In reality, the feedback given has been positive, with several participants contending that it has validated the meaning embodied within their reconstructed narrative, or enabled them to understand more clearly their current difficulties.

This thesis is implicitly theoretical in nature, where different theories are read against the data, as well as data generating theory that adds to existing conceptual frameworks. In that respect, and as already detailed in Chapter One, page 4, the literature review process has been led by the findings embedded within the narratives. This has negated the need for a separate literature review chapter. I hope that the thesis illuminates the incredible resilience and resourcefulness of the participants, who have demonstrated an ability to manage their lives in the face of adversity. Below, I introduce you to the narrators that have contributed to this vast tapestry of jointly constructed meaning.

g. The narrators

Lyn was born in Singapore, but grew up in west London, where she went to school. She lost most of her hearing at the age of eight as a result of meningitis. She studied biochemistry at university, followed by a PhD in molecular biology and now works in a university department of bioethics where one of her main research interests is disability. At various times in the past she worked in public education, packed records, was a consultant to the

pharmaceutical industry, a translator, and a typist in the complaints departments of a sweet factory. She lives with her partner, who is a musician, and one cat. She enjoys hiking, playing the saxophone, is a member of the Quaker church and tries not to take herself too seriously.

Jean was born in the UK and is now in her early 40's. She attended mainstream primary and secondary education and left school at 17 to pursue her interest in art. She studied art at college, and now works as a trainer, researcher and artist, with a particular interests in feminism, queer theory and disability politics. She continues to juggle her freelance training consultancy business, visual arts practice and responsibilities as a mother.

Chloe was born in Germany into an army existence, so as a child she lived in a number of different countries. She is an active member of the disabled people's movement and particularly enjoys the camaraderie of demonstrations. She currently lives in the northeast with her daughter who also has an impairment. She gets great pleasure from music, art, writing her own poetry and witnessing her daughter's own resistance to disability oppression.

Thomas was raised in a close-knit mining community in the Midlands where he lived with his large extended family. On leaving school, he worked in the coal mine until he was made redundant some years later. He has Asperger's syndrome, which was diagnosed later in life. This diagnosis helped him make sense of a number of childhood experiences, particularly his struggles within the education system. He has a number of children, two of whom also have Asperger's syndrome, and he endeavours to ensure that they receive a positive school experience. He lives with his partner and is an avid reader, writer of poetry, and has published in a number of poetry magazines.

Lizzie was born in India where she lived with both her parents and an older sister. She came to the UK in early childhood for exploratory surgery and then was subsequently educated here in a number of mainstream schools, where she found other children's reactions to her impairment difficult. She is a

member of the disabled people's movement, feels passionately about children's rights and is a campaigner on a number of other equality related issues. She currently lives with her partner and two children in the south of England, where she works as a trainer, consultant and writer.

May grew up in the north of England and was educated at residential school between the ages of four and eight. Despite the difficulties of being cared for within an institution, she made some positive and supportive friendships there. She is now in her 30's and works to support disabled people in making positive life choices. She enjoys spending time with friends and is particularly close to her sister.

Josh attended a mainstream primary school as a child, and was then inappropriately placed within a "special" school, where he felt he received an inferior level of education, which failed to recognise his academic ability. Having encountered many barriers to finding employment himself, he now works in the field of disability and employment; helping others challenge those barriers that he once faced. He has campaigned for and worked towards the establishment of better counselling facilities for adults who were sexually abused in childhood, particularly men who may find it more difficult to engage with counselling services. He is now in his 40's and lives with his wife and two daughters in the Midlands.

CHAPTER THREE: NARRATIVES OF POWER

In this chapter I will be arguing, uncontroversially, that the sexual abuse of disabled children constitutes an abuse of power by adults, or older children of significant age difference, who use and abuse their positions to gain some level of self-satisfaction. But, unlike many writers, I will be emphasising the cultural context of indifference to disabled children's need for protection from that abuse. I contend that the societal devaluation of children (Chapter One, pages 18-19) and the societal devaluation of disabled individuals (Chapter One, pages 15-18) can conspire to produce questionable professional practices, which sometimes result in abuse, and dubious justification by abusers for their actions. Child sexual abuse, in that sense, happens to be just one potential outcome of the dysfunctional power relations operating within these systems, with impairment providing the necessary opportunity and/or justification.

In terms of the structure of this chapter, and building on the social context detailed in Chapter One, I will begin by examining participants' experiences of large organisations and consider the ways in which they were objectified and marginalised within these systems. In particular, I will discuss their encounters with the medical profession, education systems, local authorities and the military. I will then move on to look at the position of the perpetrator; including the part that impairment was perceived to have played in their abuse experience and the strategies that perpetrators employed to ensure their compliance.

Following on from this, I will explore the position of the disabled child who, because of their family circumstances, can run an increased risk of becoming exposed to some of society's negative attitudes relating to impairment. One of the things that the chapter will illustrate is the ways in which being construed as a "problem" effects how the disabled child perceives the abuse experience. It further determines, in some situations, their attachment to primary care givers and their ability to "speak out" about the experience.

Another issue, which becomes apparent, is the way in which a compromised attachment can increase the risk of sexual abuse outside the family.

I choose to work the chapter in this way, and emphasise the social and cultural context of the issue, because it signifies, I believe, a desire to move the focus of causality away from pathologising and individualising notions of the “vulnerable disabled child” and back into society, where it belongs. It also encapsulates the end game of a personal journey that all participants have been involved in throughout their life and which is eloquently described by Lizzie:

“Today, having a perspective acquired through my experience of counselling and disability politics makes it easier to cope with, because it’s the whole thing about **the spotlight is not on me**, and I don’t have to understand the whole thing through the filter of myself.”
Lizzie

a. Narratives of organisational power

Organisational power, according to writers such as Salaman (1979), is embedded within the wider social structures of society and, in this chapter, I argue that it is littered with the same prejudicial assumptions about validity and ability, with organisational prejudices reflecting those present within the larger society. Having set the societal context for this study in Chapter One (pages 15-19) and having made a relational link, I will now endeavour to discuss the variant manifestations of organisational power that have been highlighted by participants in this study by taking each of these organisational settings separately.

i) Medical objects: “accidentally she could have killed me, and she could also have killed me on purpose too”

All participants had some contact with the medical profession in childhood, and a number felt mistreated in varying ways. These abuses of power ranged

from the aggressive administration of medical treatments to actual sexual abuse and the witnessing of infanticide. Below, both Jean and Lizzie describe incidents of child abuse experienced in hospital settings where they were resident for prolonged periods of time for the investigation of their physical impairment. For Jean, whose first period of hospitalisation lasted just under six months, she recovered memories of being abused in differing ways by a number of health care professionals. Here she details her experiences of, what she refers to as, medical abuse:

“They tied me into a cot, they put on my right leg what’s known as a ‘Jonathon splint’, which stretches and keeps your leg straight. They were also testing me for different things. I was allergic to the plaster they used to attach the splint to my leg, so that when they took that off, it just took off the top layer of my skin, so I had raw wounds from that. I wasn’t getting the pain relief that I should have been getting and I wasn’t being fed properly. I was hungry and thirsty a lot of the time. I don’t know why they tied me into the cot; I think it was to stop me moving about.”

Jean

She also describes incidents of sexual abuse, which have a ritualistic quality to them:

“They had a variety of nursing staff there and they had quite a few nuns who were medically qualified, who were part of the nursing staff, I think. There was one nun there who abused me, repeatedly over that time, in a variety of ways. One of them was enemas, and I now think that they were giving me enemas because I was constipated due to lack of movement. But the way she was doing them was sexually abusive: she did it in a very rough way, so that I was injured by her roughness.....and one of the things that she would do would be to put her rosary beads inside my rectum and then pull them out very fast, and that was all a part of this ritual that she created around the enema: and it was about getting me clean and getting the ‘devil’ out of me. It was very painful; physically painful, and very frightening because she went from, at times, being, kind of, very strapped down emotionally, talking in a quiet voice and mumbling prayer, then it would become quite frenzied. So she seemed out of control and all over the place. It was very frightening, obviously, and physically very painful. She would do stuff with my shit: there were times when she would put shit in my mouth; that was part of the

whole 'exorcism' thing that she was doing. That was one kind of abusive behaviour that I experienced very frequently."

Jean

Within these next two quotes Jean talks about incidents of physical abuse; the first incident perpetrated by the same member of staff who performed enemas, and the second by other staff members:

"I would be sitting in this wide tub and she would be pouring water all over me, and also pushing me down. She would grab the back of my head and my chest and push me down into the water. So I would be spluttering and trying to breathe, and not being able to breathe. And, again, all the sort of frenzied religious stuff was happening in what she was saying to me: full of hate. Hatefulness was the thing that came across so clearly to me. Of course, I got better at being able to time my breathing and predict what she was going to do, but it's very hard to do that because there was not a fixed pattern to it, and part of what she was trying to do was to push it, you know, to shock the 'devil' out of me. I realise now, looking back on it, how lucky I was because, accidentally, she could have killed me and she could have killed me on purpose too. The injuries to my anus would sting in the water. She also would pour extremes of hot and cold water over my head, and sometimes salt-water, it was very confusing and very frightening. So, that also happened on a regular basis: I think probably daily, or every couple of days that would happen. That would usually happen after the anal abuse, which would make sense that she would do an enema and then give me a bath."

Jean

"But the other thing that happened, and again I don't understand this, this wasn't the nun, I don't know who this was, but somebody, at some point, did something physical with me that meant that I was swung and came really close to a wall, a gloss painted wall. The memory that I've got of it is that I put my hands out and hit the wall with the palms of my hands, and if you do that quite hard you have that particular kind of stinging sensation, and I remember that I was held by my ankles, which was very painful because of the impairment stuff I had going on. I think that was a man and I think there was more than one of them, but that is very foggy, I still haven't really put that one together, and I don't know if I ever will."

Jean

Lizzie's story is similar in the sense that she too was hospitalised for a prolonged period of time for exploratory surgery and during that period of

hospitalisation she was sexually abused and physically abused by a night nurse. She offers less explicit details of her abuse than Jean but, when relaying information about how the memory of her abuse was recovered, she describes being able to remember other children also being physically abused on her ward:

"I was brought back at the age of about fourteen months and fairly promptly put into hospital for an exploratory operation and also for a frog plaster. And what I have uncovered, starting when I was something like in my late thirties, yeah, in my late thirties, I uncovered the abuse and that it was a night nurse. I was in hospital for four months and it was in the days of parents visiting for an hour a week, and it was god knows where, but a long way from where they lived, and there was no awareness of the issue then, issues to do with abuse. So I don't think my parents could have known or guessed or worried."

Lizzie

".....one of the things that my abuser did in hospital.....because he didn't only sexually abuse me, most of them don't, do they? I think one of the things he used to do was hit kids on the head, because if you do that you don't leave a mark, the mark is hidden by the hair....."

Lizzie

Jean does not describe witnessing other children being abused during this first experience of hospital, but comments on the general atmosphere of the place where children were constantly crying; a cry she contends was "trauma cry." What Jean does describe, however, is her bearing witness to the murder, by suffocation, of another disabled child in a cot next to hers. She later analyses this incident's relevance to the medical treatment of disabled children today:

"But the worst thing that happened was that I saw two male medics take the life of a child in the cot next to me. It's still a really difficult one for me. I saw, in the dark, two white coats come in and they were mumbling, speaking in low voices, and they came to the cot next to me. I saw one of them put his hand over the child's mouth, covering the mouth and nose, and I saw the alarm in the eyes of the child and some 'convulsion' type movements, and then the child went still. They picked him up by holding his clothes at his chest, so his limbs were

dangling, and then they took him away. I think he was probably about three or four, and I think, probably, had cerebral palsy. He was very thin, and kind of lanky with dark, short hair. I always call him a 'he' - I'm not sure, of course. He had beautiful, dark brown eyes. That was terrifying. It was actually, at the time, terrifying, and I know it's very shocking, and I know it's very difficult for a lot of people to believe, but it was absolutely horrendous. I mean, I know that that was happening and still does: that severely disabled infants often are left and given no water and food, but this was actually taking a child's life, this was suffocation. I've since read of a woman who witnessed a child killed by drowning. That woman was also talking about the sixties. I'm not saying that that kind of eugenic murder is happening now, in that way. It may not be, there's other ways that they do it: I mean there is pre natal scanning and abortion isn't there; they are quite effective ones. There is also lack of resuscitation. The TLC one: tender loving care and no food and water, is still commonly used."

Jean

Participants also spoke about other objectifying medical practices and, here, May and Jean describe their experiences of attending medical consultations where they were treated with little sensitivity and as medical curiosities. Additionally, May makes linkage between these objectifying practices and later victimisation:

"I also think that, like other disabled people, I lacked a sense of my own body belonging to me, and being private, of not having to be touched if I didn't want to be. This came from having to have many visits to the doctors and physiotherapists, and needing help to do things. I remember being paraded in front of doctors with very little on and feeling I was a thing for discussion rather than a person in my own right. This feeling got stronger as I got older. I was thirteen before I was given a choice about whether I kept appointments. When I exercised my choice by not going, then I was made to feel guilty by other professionals, which reinforced my feelings of 'what is the point?' This lack of a sense that your body belongs to you is an issue that non-disabled children do not have to face. And, again, I can't say that this makes us more of a target, but it does make us better victims as we are less likely to object or tell."

May

"In one hospital I was photographed because I'm quite unusual, because I have such extreme symptoms in one joint, and also because after my surgery one of my toes stopped growing; so one of my toes is the same size as it was when I was nine. And they said,

‘Oh, that’s interesting. How did that happen?’ Nobody would actually acknowledge any possible connection to the surgery. Many other disabled people talk of similar experiences of being examined and photographed in an abusive way.”

Jean

Jean also describes other examples of depersonalised medical intervention, including the over-prescribing of medication, which resulted in her subsequent hospitalisation on more than one occasion. She later describes the distressing post-operative care that was experienced when in hospital for the second time:

“A couple of times I was given too much medication and I ended up in a children’s hospital because I was a bit dopey. My mum only just told me this. She said that I was half awake, half asleep, ‘you weren’t asleep but you weren’t awake.’ She called it comatose, but it wasn’t a coma, obviously. They took me in and changed the pain medication that they had me on. That happened again when I was about eight, over Christmas time, where, again I was given too much medication.”

Jean

“I wasn’t abused in that hospital but, again, the sort of general approach to child medicine, at that time, was still quite brutal and hard for kids. I know it’s come on a lot now, you know, things like parents visiting. It was more of a child-friendly kind of atmosphere than the first hospital. But I do remember coming out of the surgery with completely blood soaked bandages on, and that was quite traumatic for me. I still really struggle with red on white.”

Jean

Finally, Josh describes another manifestation of the medical profession’s inappropriate use of their professional power. In this particular example, a doctor used his gate-keeping powers to facilitate the provision of a placement in a residential school, so creating an indirect method of dealing with Josh’s mother’s suspicions of sexual abuse:

“It was a decision made by my mother and the doctor, and the reason why it happened, I found out subsequently when I spoke to my mother, was that she was concerned that I was being abused and special school would take me out of the situation. The doctor was the one that dealt with my particular disability. I think his name might have been Clarke; he’s been dead a long time now. And she’d obviously

gone and said, 'Well look, something's not quite right.' And, of course, these days they'd send the child protection team in, and goodness knows what else, and they'd remove the child and they'd have banged him up in the nick, but in those days they didn't, did they? And so I was taken out of the situation, but they still allowed me home at holiday time to be abused."

Josh

Historically and traditionally, medicine in western society has largely operated within a hierarchical power structure, where doctors sit at the top of the pecking order, differentiated according to consultant status (Hughes and Furgusson 2000). The power of medicine itself, according to some writers, lies in its intellectual knowledge of the body (MacKay, 2003), which grants its legitimacy and permits a set of objectifying practices that society feels are justified. Functionalist theory has dominated the profession and its associated focus on cure and restoration of normal functioning, with patients being expected to be suitably attentive and compliant with the doctor's assessment and proposed treatment regime (Lupton 1994). Lupton believes that doctors are not necessarily deemed by society to be acting in an oppressive fashion, but are behaving in a way that is expected of them. It could safely be assumed that all of these doctor-patient dynamics were relevant to the parents of the children in this study, who entrusted medics with the care of their child, with a certain set of expectations regarding their own and the doctor's behaviour.

The division of the mind and body, Lupton (1994) contends, lies at the very heart of western medicine. It is responsible for many of its practices, which result in the patient becoming alienated and depersonalised (Wendell, 1996), in the same way that participants describe in this study. The patient's body is conceived of as a physiological machine, according to Cartesian commentators such as Leder (1990). It is an object which, when invaded by illness and disease, requires increasingly scientific means to prevent its demise. Consideration of drug side-effects are seen to be of secondary importance (Koch 2000). Facets of this behaviour are clearly demonstrable in Jean's experiences of over-prescribing and post-operative care.

Functionalist theory quite often equates impairment with deviancy and influences the language used by medics and their interpretations of disabled people's ability as incompetence (MacKay, 2003). Barnes (1998) and Bricher (2000) argue that the medical profession holds a disproportionate amount of power over disabled people's lives by acting, as they do, as gatekeepers to many non-medical resources. Josh's case is one such example of where the unquestioned and inappropriate use of medical power provided access to a non-medical facility as a means of dealing with suspicions of sexual abuse occurring within the family.

The power differentials, identified by many feminist writers when analysing the doctor-patient relationship for women (Roberts, 1985), are multiplied for disabled people. Begum (1996) demonstrates that within a medical setting, disabled women can regularly experience unsatisfactory relationships and medical practices that can be considered to be objectifying. In particular, and amongst other things, her participants reported a tendency to show curiosity towards impairments that the doctor had not seen before, even when the participant was visiting the health locality for some other unrelated complaint. This medical curiosity, which in Begum's research was felt to be inappropriate, has the potential to become more blatantly abusive, particularly in the case of disabled children who, as in May's case, have less power to protest. Additionally, May draws parallels between medical objectification and the potential for later victimisation.

The tendency of some medical professionals to take the views of disabled people less seriously, as demonstrated in Crisp's study (2000), is even more problematic for disabled children. Despite work indicating disabled children's desire to be informed about treatment and be fully included in medical consultations (Garth and Aroni, 2003), Davis (2004) argues that disabled children's perspectives continue to be overlooked because of medical assumptions relating to competency and personal agency. Consequently, hospitalisations are frequently experienced by children as traumatic because of a general lack of sensitivity to their comfort and needs (Closs, 1998) - an issue raised in Jean's narrative episodes. Whilst the duration of

hospitalisation has, thankfully, been shortened in more recent times due to a trend in day-patient admissions, not much more than thirty years ago disabled children were routinely hospitalised for months at a time with, seemingly, little awareness of the issues of attachment and child protection (Oswin 1971). Both of these factors were especially relevant for Jean and Lizzie.

Within medical discourse, quality of life definitions predominate medical decision making, health planning and resource allocation, and become particularly salient where conditions are seen to deviate from what is considered to be the societal norm (Koch, 2000). For disabled people, devaluing societal assumptions relating to poor/no quality of life exist (Marks, 1999), which can then culminate, according to a number of writers, in a variety of questionable medical practices, which are sanctioned by medicine's scientific knowledge base. These practices can include such things as withholding treatment (Albrecht, 2001), aggressively applying treatment for those considered worthy (Koch, 2000) and the utilisation of measures designed to eliminate impairment such as: pre-natal screening, advise on aborting disabled foetuses approaching full gestation, withholding treatment or nutrition from disabled babies, and infanticide (Crow, 1996; Wolfensberger 1994). These issues have relevance for both Jean's experiences and observations whilst in hospital.

Practices designed to take the life of a severely impaired child, as witnessed by Jean, has been the subject of conflicting debate. Within contemporary society, two positions seem to exist in relation to the question of whether or not children with severe impairment should be given life-promoting treatment or, instead, be subjected to medical practices designed to take lives. Pro-life advocates believe in every individual's right to treatment, with any attempt to take life (in whatever form) being intrinsically wrong (Lee 2002). Arguments defending practices that terminate a disabled child's life, again, are based in quality of life discourse relating to the experience of the disabled child, the parents or other family members (Singer 1993). This is in addition to the economic cost of providing long-term care for such children. In fact, the prizing of healthy babies, who can make future economic contributions, is

implicit in the opening paragraph of the *National Service Framework for Children, Young People and Maternity Services* (Department of Health, 2004). Singer (1993) argues that because newborns do not possess rationality, autonomy and self-consciousness the eradication of their lives cannot be equated with older children or, in fact, animals. Kuhse and Singer (1985) believe that it is far better to let a severely disabled child die in the interests of replacing them later with a non-disabled child. They see no difference between withholding treatment and actively taking lives, believing, perhaps, the latter to be more humane.

A reconsideration of the morality of infanticide promoted in the earlier writings of authors, such as Singer (1993), has generated some controversy in recent years, where the views of explicitly disablist writers have, increasingly, come under attack (McMahan, 2002). In addition to human right's discourse, the disabled people's movement has begun to offer other forms of challenge to euthanistic practices, with authors such as Shakespeare (1998) presenting political opposition, and Macfarlane (1994) raising awareness using a narrative format. Shakespeare (1998) argues that since the removal of disabled children from society is neither "feasible or desirable," it is time for society to promote more positive measures to include and value disabled children, with new parents being given the appropriate level of financial and welfare provision to support their parenting in a more fulfilling manner. Additionally, Shakespeare would also advocate disability equality training for geneticists and obstetricians, the people who have a major influence on prospective parents' decisions in the early stages of pregnancy.

In relation to sexual abuse occurring within a hospital setting, as in Jean's and Lizzie's experience, Sullivan and Beech (2000) argue that any organisation or institution where children are cared for are vulnerable to infiltration by paedophiles, both male and female. Despite the introduction of such measures as the police check system, abusers still manage to slip through the net. Wardhaugh and Wilding (1993), who build on the work of Goffman (1961) and Martin (1984), broaden the analysis of institutional abuse of children from the exclusive focus on the individual psychopathology of the perpetrator, to

the consideration of organisational structures and processes which harbour practices such as sexual abuse and infanticide. They describe this phenomenon as the “corruption of care” and cite eight factors which operate within large organisations and which play a significant part in the creation of abusive environments. Below, I present some of the factors that are particularly relevant to the abuses of disabled children occurring within hospital settings:

- For children, particularly disabled children, abused in hospitals, they can come to be seen as less fully human. Neutralisation of the normal feelings of compassion and sensitivity to others’ pain and suffering create dehumanisation and moral distance (page 6).
- Children in hospital, particularly disabled children, have little power or influence over their situation, by contrast to staff who have absolute power over them, but who, at the same time, may feel that they are rendered powerless by their organisation (page 11).
- The resources and facilities made available to devalued sectors of society, such as disabled people, reflect the low value placed on their work and their clients. Shortage of resources create situations of risk, since emphasis is placed on control and order and keeping the lid on the system (page 14).
- Clear organisational aims and objectives help provide a framework for desirable working practices. Without these aims and objectives the rights of users and ideas of good practice are compromised and too much depends on the attitudes of the individual (page 18).
- Tightly knit organisations can easily stifle criticism and complaints and nurture unhealthy cultures. The ingrained sense of staff solidarity blocks challenges, even if others do not approve of the ill treatment in question (page 21).

- Hierarchical structures make complaints from below difficult to air. Additionally, those whose responsibility it is to set standards are distant to where practice is delivered (page 25).

As indicated, perpetrators are generally drawn to organisations such as hospitals where hospital structure, hospital culture and internal politics can provide a cover for their abusive activities. It can safely be assumed that some of these dynamics were prevalent in both of the hospital settings where Lizzie and Jean were cared for. Of course, many of these factors also apply to other institutions where disabled children live for significant periods of their time, particularly residential schools, an issue which will be discussed further in the next section.

ii) Mainstream and “special” schools: “If they’ve got a disability they’re probably thick anyway”

All of the participants in this study attended mainstream schools, with two of the seven also spending a period of time at a residential school. The two participants who attended residential school spoke of being objectified, devalued and abused by the system. These abuses/misuses of power were related to the school’s failure to provide a level of education that was consistent with their academic ability, the child being socialised by the institution into compliant and unchallenging behaviour, and the school’s failure to detect sexual abuse perpetrated by another, much older, pupil.

Equally, the participants who attended mainstream schools also felt let down by the education system. For children with visible impairments, these failures included a lack of input from teaching staff when non-disabled peers were bullying that child. They also included a lack of awareness of the implications of impairment for the child’s ability to participate in classroom activities. For children with hidden impairments, educational struggles and the consequential frustration meant that their behaviour was misread as naughtiness and disruptiveness, with their educational requirements not being adequately addressed. In a number of cases, the teaching staff, who were

aware that the child was experiencing some level of personal difficulty, assisted by providing the child with a level of general support (for which the child was grateful) rather than discussing the situation with other outside agencies invested with the powers to investigate further.

I will begin by considering residential educational settings. As can be seen from his quotes, Josh's overwhelming feeling about residential school was that it deprived him of an education, and that this placement wouldn't have been made if it were not for his sexual abuse (page 61). It illustrates the amalgamation of disadvantage that can occur for disabled children who are sexually abused:

"...no educational challenges, no exam system in place for bright disabled people; because if they've got a disability they're probably thick anyway. I mean there were teachers and professionals with that attitude, which was, and is, an absolute disgrace."

Josh

"Because of my abuse, I didn't get an education because I was easy to slot into a school for disabled people. The abuse made it worse for me, in that respect. The fact that I didn't have any qualifications, that I left totally confused at sixteen, totally confused about everything."

Josh

May's criticisms of residential schools relate to the controlling institutional regime, with which children were expected to comply. She refers to the consequences of this for her ability to subsequently disclose abuse:

"My experience of boarding school also made it less likely I would tell anyone about everything that was happening to me at home. Boarding school conditions you to fit into a system. I remember being told 'you are doing it because we say so.' If I complained there was always a consequence, the same was true if you had a disagreement with a member of staff, or said you didn't like something someone was doing. So you learned to put up and shut up. I felt very much that there was no point in saying anything because it would only make things worse."

May

For Josh, who was placed in residential school in order to protect him from suspicions of sexual abuse at home, the placement turned out to be equally as abusive, and below he describes the abuse experience and his attempts to mitigate the situation:

“...but when I was about thirteen, I was abused by one of the older boys as well. He was probably sixteen; perhaps he was staying on longer so he could have been seventeen actually, and that was a bit scary. That wasn’t anal, that was just masturbation. At these times I was the submissive one, only interested in mutual masturbation because then it would be over quickly. No anal or oral sex because I had to ensure that it was over as fast as possible. Although I used strategies to protect myself so that I didn’t have to endure the pain of penetrative sex, I did feel I was being done to yet again.”

Josh

For the children attending mainstream schools, who also included Josh and May, the experience, as already referred to, was also unsatisfactory in a number of ways. Below, Jean details her experiences of being bullied by non-disabled children, and the staff’s unwillingness to intervene despite having observed the situation:

“I got very little help from members of staff, no help at all with it. And again that’s one of the things that I would say about integration for disabled kids. Yeah, I’m totally in favour of it, absolutely one hundred percent, but we need to be paying attention to those issues. I know that there is more awareness of that now, but for me it was very hard. For a while, at my primary school, there were two other disabled girls, and that was good, that made things a bit easier, it wasn’t just me. We were all bullied and it was mostly a kind of low level bullying that teachers did nothing about. They heard it all, I mean, I was called ‘spaz’ all the time and ‘hop along’ and nothing was done about that, no comment was made.”

Jean

Josh describes the general lack of understanding of his impairment and the inappropriate expectation that he participated in physical education with no extra support or supervision. This lack of understanding also contributed, on occasions, to the misinterpretation of its effect as naughtiness or cheekiness:

“Sports I used to find really, really difficult because they were expecting you to climb up these damn ropes, and they expected you to climb up these wooden things on the walls. They didn’t make any special dispensation for me, and they should have done. The fact that I couldn’t run as fast as somebody else, it was insensitivity, and so I suppose sports was the worst.”

Josh

“And because of my disability, I sometimes ended up with a smirk on my face, which was no good in school because they’d chuck the board rubber down the back of the classroom, and I had the slipper a few times purely for me just being me.”

Josh

Thomas and Chloe’s difficulties related to their unrecognised impairments, which required extra support and encouragement. For Thomas, his behaviour was seen as difficult and disruptive. For Chloe, her attempts to get help were interpreted as attention-seeking behaviours, with this assessment being constructed without Chloe’s involvement in the assessment process, despite her age. Both of these participants also believed that their learning issues were exacerbated by their sexual abuse:

“I would often run riot with teachers and could even be violent. This made life very difficult for me since I was always being put in isolation, preventing me from disrupting lessons. Looking back, my Asperger’s made schooling an awful experience.”

Thomas

“I was at secondary school and was trying to settle down and behave myself. I was trying hard in as many lessons as possible and started to get decent grades. I was still in the lowest group, but I was now among the top six in most of my subjects, apart from maths. My reading continued to be a bit of problem and my English teacher mentioned this to my stepfather at a school governors meeting and, god, did he go on about it. He started making me sit with a book for one hour each night at home. I would have to read a chapter to myself and then tell him what it was about. He would come to my room to hear what I had to say and once I’d finished he would bugger me or do some other perverted act. I wouldn’t read a word of any book he gave me; I’d lie on my bed and listen to the radio. He’d go crazy at me: shouting, punching and slapping me at my failure to answer his questions.”

Thomas

"The teacher talked to me, I told her what it was, they tried to get me help and they brought an educational psychologist in who talked to some of my teachers, not the one I'd talked to, and not me. And they said, 'Oh, we think she might have schizophrenia,' which my mum told me a couple of years ago. And another teacher said, 'Oh no, she's just getting carried away with a drama project.'"

Chloe

"When I told her (the teacher) I thought, 'what a relief someone's going to help me' and then all these people came along that didn't help me, and I had to sit in the sick bay, in the corridor. Our school was in an old hospital and I had to sit in the corridor on a hard chair for about an hour while they were all in this room, a bunch of people who mostly didn't know me, talking about me, but not once involving me. Then they came out and I got took back to the head of year's office and told off for wasting everybody's time. So, yeah, I told her that my head was different, but this is all around a similar time to when I did have what I, for ages, didn't realise was probably the most significant sexual abuse experience I've been subjected to."

Chloe

For both Lyn and Thomas, they talked about other issues, which did not relate directly to education, but were, nevertheless, questionable professional practices. At both of these individual's schools, teachers saw the child's distress and attempted to deal with it in their own particular way, as opposed to passing the information on to the appropriate authorities. This response was probably typical for that time, and was perhaps relevant to a desire not to compromise their professional role. It did result, for Lyn, in feeling increasingly isolated and needing to "up the stakes" in order for her situation to be recognised:

"She went to meetings (Lyn's mother), and one time she went away for a week's course on meditation, and when that happened I went to this teacher and said, 'Could I come and baby-sit for a week?' I remember, she said, 'Why?' I said, 'My mum's going away and I don't want to be home with my dad.' And there was this little beat of a pause and she said, 'That's fine, you come,' and I did. And after that, in my sixth-form time, there were periods when I would go and stay over-night there, and the excuse was always that I was babysitting. Years and years later, I said to her, 'Why didn't you pick it up?' and she said that she didn't know what to do; it wasn't something that people were given guidelines about. She said that I was a topic of conversation in the staff room; people knew that there was something

seriously wrong and they just didn't know how to handle it, and they just didn't want to ask a direct question because they were frightened of getting it wrong. I can understand the not knowing what to do, being afraid that they would actually make things much worse. Perhaps there was a sense of 'well, if it's something at home, then she's nearly at university, and if we do something now then it could screw up 'A' levels and stuff, so if we can sort of just keep going like this, it will be okay in the end.' I don't know. She said it wasn't that people didn't notice, they did. At the time, I felt nobody was noticing anything at all, and that made me feel very lost, and it made me feel that I had to escalate stuff. But I think it would have been helpful if somebody had said there's obviously something going on."

Lyn

"He (the teacher) knew I hated my stepfather, he knew that something was wrong in my home life, and asked me what the problem was many times, or asked me how I'd got the cuts and bruises. He told my stepfather of his concerns, making out that he thought I was being bullied, in his own way warning him that he knew something was very wrong. It didn't stop the abuse but at least he tried, he was on my side, he cared about me."

Thomas

By way of contextualising participants' narrative accounts of education systems, Kliever and Drake (1998) offer a helpful Marxist analysis of the historical development of the segregated education system within the UK. This system was viewed as the most appropriate way of educating disabled children until recent times. Its evolution is theorised as part of a larger process of institutionalisation, which attempted to exert some form of control over people who offered a threat to societal homogeneity. Kliever and Drake contend that this educational development had its scientific base in instruments such as psychometric testing, which then provided the necessary justification for moving disabled children from a segregated classroom situation to an educational institution, which had the same low educational expectations that are described by Josh.

The Warnock Report (DES 1978) signified the beginnings of a shift in ideology relating to educational provision for disabled children, with parts of it actively encouraging the inclusion of disabled children in mainstream education (Davis and Watson, 2001). However, despite this, the medical model of disability and

its accompanying devaluing attitudes have prevailed and continue to prevail in the current education system. This has created a situation whereby “special educational needs” discourse still predominates in both mainstream and segregated schooling, operating on the same objectifying continuum of normality – abnormality, with an emphasis on deficit (Shaw, 1998). This is at the same time as pedalling educational policies that are promoting “inclusion.” The indifference located in this current educational philosophy becomes apparent when analysing the contradictory structures that fail to sustain it (Davis and Watson, 2001).

Focusing first on “special” education, Kliwer and Drake (1998) argue that, historically, all segregated educational institutions operated on an ideology of control, which served to promote compliance and deter any form of challenge. This issue becomes apparent in May’s quote. Additionally, they contend that there has also been a history of support for educational practices which have promoted the use of controlling and dominating behaviour by staff, sanctioned through the application of crude and objectifying psychological theory, which approved Pavlovian-type behavioural methods to obtain acquiescence.

Wardhaugh and Wilding’s (1993) analysis of the “corruption of care,” discussed in the previous section on abuse within hospital settings, can equally be applied to residential educational settings. There is the potential for children, particularly newcomers, to have little power. This is in contrast to adults and older children, whose position of power can be used and abused in varying ways, as illustrated by Josh’s experience of sexual abuse by an older child resident at his school.

Similar to the experiences of Josh and May, descriptions of controlling practices exercised in segregated educational settings are voiced in the narratives of other survivors of these institutions (French and Swain, 2000; Zivirsek, 2002; Durham, 2003). When considering the impact of living under such circumstances, Roets and Van Hove (2003) write that “If people are frequently in situations in which they have no control, their expectation and belief that they can do anything to effect or change events wears off.” As

already indicated, this is a view endorsed in May's narrative account, where she makes linkage between this and her later inability to disclose sexual abuse. Davis and Watson (2001) contend that some of these facets of educational existence can still be observed today in a similar, more moderated form. It is argued, by some, that the unquestioned autonomy and lack of accountability in some residential schools can harbour abusive behaviours. This is aided and abetted by the lack of clarity operating within local authorities regarding their placement-reviewing arrangements (Morris et al., 2002).

In fact, Morris et al. (2002) found in their study much inconsistency in the local authorities' interpretations of their statutory responsibility once a child had been placed in residential school. Children funded solely by education departments received minimal, if any, input. In jointly funded arrangements assumptions were made about social services taking the lead role yet "looked after" regulations were rarely complied with by social services, despite one in ten children being of primary school age. The reviewing regulations advocated by the *Children Act 1989*, if implemented appropriately by social services, go some way in providing a structural mechanism for facilitating the promotion of the welfare of children that are cared for away from home. If neglected, however, they fail to afford children any form of protection, particularly disabled children with limited communication opportunities. For children such as Josh and May, who were educated residentially before the introduction of reviewing guidelines, there were, in effect, no protective measures in existence to ensure their physical and emotional safety.

Within mainstream education, the difficulties encountered by participants in this study still have some relevance for disabled children today. Despite the current trend towards inclusive education, the process remains problematic, with research indicating a range of difficulties relating to its implementation. Following a disabled boy's exclusion from a mainstream school in the US, Dorries and Haller (2001) detail an assortment of narratives that subsequently appeared in the media. The authors felt that these narratives reflected social attitudes. They ranged from positive arguments, such as the promotion of

increased tolerance of diversity for non-disabled children, to more negative interpretations, which supported his exclusion. These negatives focussed on, amongst other things, the disruptive influence of disabled children in the classroom, and the potential for lowering educational standards. The narratives also highlighted resource issues, with some parties arguing, rightly, that poorly implemented policy is destined to disadvantage disabled children by placing them in unsupported situations where they can become the target of others' hostility. These narratives reflect much of the current debate within the British education system, with the latter point having particular relevance to some participants in this study who were unsupported at school.

Davis and Watson's study (2001) highlights the contradictions inherent within the "difference discourse" currently circulating within mainstream schools. Typically, identity was described in terms of labels, yet despite this apparent acknowledgement of difference, a child's behaviour/performance was measured against physical and cognitive norms. In their study the process was further complicated by other stigmatising strategies, such as the creation of segregated special units within an inclusive educational setting. They found bullying behaviour towards disabled children, such as that experienced by Jean in this study, being interpreted in terms of the disabled child's shortcomings. This justified the continued bullying behaviour by non-disabled children. Little attention was paid to negative subcultures that developed and, in a sense, were nurtured between children by the organisation. In Jean's experience, the lack of challenge by staff members towards non-disabled children's disablist language was just one example of the ways in which disabling cultures develop.

Despite the difficulties that can be created by a labelling culture, two participants in this study illustrated the fact that diagnostic categorisation can, in certain instances, be a useful tool. For teachers, identifying an impairment can provide an increased understanding of the prevailing issues for children with hidden impairments. It can also facilitate access to the necessary resources that can support learning (Malloy and Vasil, 2002) and promote an inclusive atmosphere within the classroom situation, so preventing other

labels such as disruptive, naughty and attention seeking. For both Chloe and Thomas, the recognition of their educational difficulties and the acquirement of a “label” could have proved to be of some benefit to them if the assessment process had been conducted in a sensitive and enabling manner. The lack of recognition was probably symptomatic of a general failure to understand, at that time, impairments that are now classified as autistic spectrum disorders.

The other issue highlighted in the participants’ narratives, when relaying experiences of education systems, was the teacher’s failings in their professional responsibility to pass on concerns about child abuse to the appropriate agencies. The situation today is still relevant to the experiences of participants in this study as there continues to be significant barriers to reporting child protection concerns (O’Toole et al., 1999; Kenny, 2001). Kenny (2001) believes that the deterrents to reporting include: concerns about being supported by senior staff members, fear of making inaccurate reports and concerns about the child protection service’s ability to support the child both during and after the investigation process.

Both Kenny (2001) and O’Toole et al. (1999) identify the necessity for staff training in the recognition of symptomatology and the correct reporting procedures, with an increased awareness of their professional responsibility to the child. Baginsky (2003) argues that this training should not only take place whilst students are undertaking their teacher training, but also should continue throughout their professional practice. Such training, she believes, would increase the teacher’s confidence to become effective partners in the child protection process. Training and clear guidance regarding areas of professional responsibility would have, undoubtedly, helped the teaching staff in both Lyn and Thomas’s schools.

iii) A lack of voice: “they said I would never manage”

Within this section I discuss the communication difficulties encountered by participants when dealing with certain key organisations other than health and

education. As children, the participants' experiences of welfare agencies were typified by the agencies' inability to: engage with the child/young person in a meaningful way, hear their concerns and meet their needs. As an adult, one participant spoke about her personal battle to make an official complaint to the military police regarding her abuse and for that complaint to be dealt with appropriately.

I begin with May's narrative episodes, which relate to her involvement with social services. This agency appeared to sidestep their responsibilities by both marginalising May's views and prioritising, instead, the views of her parents. As a consequence, May's dependence on her family and the duration of her abuse were extended, an issue complicated further by a lack of adapted housing stock:

"I also think that disabled people have to face issues with social services that others don't (although I hope that this has changed now). I tried to move out at an early age because I felt that this was the best way to change things. I approached my social worker, who then went to my parents to ask what they thought. Of course they said that I would never manage. I was told that I was better off at home. Other non-disabled people would have said, 'I'm having problems at home and want to move,' and been supported. I know this because friends that I have known have done this."

May

"My abuse lasted until I was into my twenties; this was a direct result of my disability. Like I said, I had been trying to move out from an early age but the lack of suitable properties meant I spent longer on the housing list than other people would. Anyone else in my position would have been able to move in anywhere, but I couldn't. My health was worse so I needed more help, and I think that this makes social services reluctant to re-house you because of the cost. My way of coping with things during this time was to stay away from home as much as possible."

May

Within these next quotes, Lyn talks about her family's complex relationship with social workers, who also dealt with her mother's impairment-related needs. For her self, there was often an exclusive focus on impairment to the neglect of other potential areas of difficulty:

"The relationship with social services was also very complex; my mother relied on their support, but there was also a resentment of the control that they had to provide support. Going to social services would have been a betrayal as well. Maybe one of the reasons that things didn't get noticed was that whenever I cropped up in the problem category it was always with the focus of hearing loss and the provision of hearing aids, and people maybe felt that once they'd done that bit, they'd done what was necessary. They were so concerned that I should hear enough at school and at university to succeed, and if that was achieved then the rest of it was almost too much to take on board."

Lyn

"She went to day centres, so we always had a social worker, and yet I don't think anybody ever asked me really. If somebody had asked me directly if there was anything I would like to stop, then I would have been able to say that 'I wish he wouldn't drink so much, I wish he wouldn't grope me, I wish he'd listen to me,' and that kind of thing. And that might have given them a clue."

Lyn

Lyn also talks about the lack of provision of lip reading classes and its impact on her ability to communicate and socialise with others outside the family:

"I think that there were reasons, not just to do with the family situation, that I was more isolated from other children. I did have difficulty communicating with people outside my family for a long time; my lip reading wasn't very good and I wasn't offered any lip reading classes. I could usually understand my mother; I often had difficulty understanding my father, and people outside the family were often quite difficult. So I read a lot, I didn't really have many friends, and the habit of speaking to people about things stopped, I think. It's not the only reason, but it sort of compounded it and made the barriers harder."

Lyn

Notwithstanding the necessity for disability benefits, which are designed to enable disabled people to access services on equal terms, May describes a situation whereby her parent's misuse of her money prevented her from socialising with other children and participating in community life. She also believes this situation affected her transition to financial independence:

"I was taken out of school because disability benefits came into being. I have recently been told that a number of people in the family were arguing about who should look after me, and I can only assume that money was the real factor as no one had been interested up until then. I think that money can be a big issue in the treatment of disabled children. For many, like myself, parents cash benefits, which then become part of the family income. Parents then become reluctant to do things and take disabled children, teenagers or adults out of the family because this will then affect the level of income that they have. This is an issue only faced by people with disabilities, as other people only get money when they are adults, so their family do not get used to having their money. It also means they do not have to battle to get financial independence."

May

As a young adult, Chloe talks about the difficulties that she encountered when trying to report her sexual abuse. The abuse happened whilst living in an army camp and the adult concerned, she now realises, was working as part of an organised paedophile ring. It was only when she spoke to Victim Support and the civilian police that she realised that she was being fobbed off by the army, who were closing ranks and trying to protect themselves from scrutiny:

"I actually approached the army first about it, and they did everything they could to discourage me. I just rung straight out to the army police in Germany, because that's where it happened, and I knew that the crime would have to be investigated where it happened. I'd taken advice from someone here quite a while ago, a policeman. I actually rung him up and sort of got bits of information, so I knew it would be investigated by the army and police. So when I decided to make a complaint I actually went straight to the Royal Military Police. They put me through to a welfare officer, and I didn't even think it was that weird really, apart from when this welfare officer starts trying to talk me out of it, 'You do realise it would be a very difficult thing, and you know people often don't get caught, and are you sure that you have got enough support in your life to be putting in a complaint?' And then I thought 'why am I talking to some fucking welfare officer? I want to talk to the police.' Anyway, in the end he said something like, 'I think you should get advice from Victim Support.' "

Chloe

"I rang Victim Support and they said, 'Oh, for god's sake, don't ring the army police again about this,' and I was really amazed that they even knew anything about this sort of issue. She said, 'You're right, the military police will have to get involved, but it might actually be better to go to the civilian police first, that are local to you, to report

the incident, so that somebody independent is also involved, because, otherwise, the army police will just take it on.' And they will also do everything they can do to stop you, is what she was implying. And when I rang up the police here they said it a lot more clearly and just said, 'No, you really need independent civilian police involved because, otherwise, they cover it up.' "

Chloe

The responsibility of local authorities to talk directly to disabled children in order to establish their thoughts and feelings is enshrined within the 1989 Children Act (Read, 2000), and further strengthened by the United Nations convention on the Rights of the Child 1989 (Mitchell and Sloper, 2001). Despite these legislative mandates, research still continues to demonstrate the local authority's resistance to these recommendations (Morris, 1999), with professional practice continuing to circumvent social workers' statutory responsibilities. Commonly, as demonstrated in May's situation, Morris (1999) found social workers were making assumptions about a disabled child/young person's ability/inability to communicate, prioritising, instead, the parental perspective, which is given more credibility. Morris argues that whilst making the parents the primary focus of social work intervention offers a positive model of working in partnership with parents, it also creates the potential to overlook disabled children's needs. These needs might include services to improve communication, the young person's desire for independent living and their general experiences, which might include child abuse.

Morris (1999) raises these issues and a number of other professional practices that conspire to render disabled children's views inaudible. These practices include a reluctance to observe children in their placements (community or residential) and, as already described in the previous section, a failure to adhere to reviewing regulations for children placed away from home. They also include the use of respite care, or other residential facilities, to deal with suspicions of child abuse happening within the family (as was Josh's experience, page 61). For those social workers who actively endeavour to obtain the child's perspective, Morris found a lack of commitment from local authorities to fund the specialist training required to facilitate effective communication, an issue that may have been a significant factor in Lyn's

situation. Additionally, Lyn's quote also raises the issue of conflicting roles and responsibilities for social workers who work with families where there is both a disabled child and a disabled parent. As indicated, this occurrence adds another level of constraint to open and honest discussion amongst all parties.

This range of barriers to effective communication operates within a massively under-funded financial context, where social workers employ overly tight eligibility criteria (Middleton, 1999). This also applies to other sectors of social services and creates situations whereby there is a lack of resources for the adaptation of housing stock.

In relation to May's fight for independent living, Morris (2004) highlights the fact that there is no legal entitlement to independent living and that despite the financial situation that local authorities face, other discriminatory factors have an impact. She argues that the assessment process undertaken is usually based on negative assumptions relating to the decision-making capacity and the associated risks.

Pascall and Hendey (2004) contend that the young person's parents are often integral to the successful transition to independent living. They can be crucial advocates for their adult children, assisting in mediation with related professionals and sometimes providing material help. They, however, describe the parents who are able to fulfil this role, as "exceptional parents" to the rule. It was the most resourced and/or resourceful individuals, with the necessary negotiating skills, that achieved independence after a long transition period. Most young disabled people, they argue, reach adulthood without savings and in poverty. For young people such as May, whose benefits were diverted into family funds, the usual difficulties can become exacerbated. This, in effect, is testimony to May's determination to overcome the numerous obstacles to her escape from an abusive family life. This misuse of benefits by carers is not an issue that the benefit agency considers important to track. Once the child is seen to fit the criteria for benefits, it is then left for the family to determine how these benefits are spent. This is

clearly an area that requires further research and also impacts upon policy provision.

In these final paragraphs I move from discussing professionals who do not ask the necessary questions to get the right answers, to those who demonstrate an inability, or a lack of desire, to hear what needs to be said. Little research exists that compares child abuse prevalence within the military to that within the civilian population. That which does exist mainly comes from the United States and concerns families who are not located overseas. Whilst much of the US research indicates lower levels of child abuse in the military (Raiha and Somia, 1997), other research, including the little which has come from the UK, indicates higher rates (Guest and Johnston, 1979).

According to Chamberlain (2003), gaining accurate prevalence data from the military is complicated by differential reporting procedures and poor data collection practices, which conspire, she believes, to create an underestimation of the problem. Additionally, as could be the case in Chloe's situation, referrals made to child protection services outside the military may never appear in military statistics. Clearly, child abuse within the military is a significant problem, which requires open and transparent structures to enable its further investigation, rather than the self-protective attitudes encountered by Chloe when trying to bring her sexual abuse to light. Equally, the military is also susceptible to penetration by paedophiles and has some of the same organisational characteristics identified by Wardhaugh and Wilding (1993), which preclude the identification and investigation of child sexual abuse within that organisation.

b. Narratives of perpetrators

A significant number of participants in this study had been sexually abused in childhood by parents or stepparents living within the family home. As already detailed in a previous section, Jean and Lizzie were abused by "care-giving" professionals who were previously unknown to them and who were working in

large organisations. For Lyn, Josh and Chloe they experienced both intra-familial and extra-familial abuse.

Both May and Josh believed that their impairment provided an increased opportunity for sexual abuse to occur, possibly without detection, and Chloe and Lyn believed that their emotional availability played a significant role in their abuse experience. Thomas and Jean felt sure that the perpetrator's hostility towards impairment had played a part in their experience by providing the necessary justifications for their actions.

Within this next section I will be investigating the participants' views on the motivations of their perpetrators, including their perceptions of the role that impairment played in the abuse experience. I will then move on to consider participants' views on the strategies that perpetrators used to ensure their compliance.

i) Understanding perpetrator behaviour: “a symbol of something else”

Most participants had little information about their abuser's background to draw upon, when considering the contributing factors to their sexual abuse, except, perhaps, for Thomas and Lyn. Although Thomas is unaware as to whether his stepfather was sexually abused as a child, he does attribute his stepfather's treatment to his upbringing, which was marked by disrupted attachments to primary caregivers and experiences of physical abuse. Thomas elaborates further on this point below:

“I do believe my stepfather was abused as a child himself; apparently he had an awful time with his stepmother. His mother died when he was seven, and he left home when he was eleven because his stepmother beat him, as he put it. He left home and went to live with his grandmother when he was eleven. And I can remember him talking one day when all the family were around and saying that he'd turned around and hit her back. He said, 'I hit the cow back, for the first time in my life, I stood up and hit her one back; she'd spent bloody years belting the hell out of me.' And I thought, that's where it

comes from, the physical abuse side, that's where it comes from. The sexual abuse, I couldn't say."

Thomas

Lyn is unaware as to whether her father had been sexually abused as a child or, in fact, physically abused, but below makes some linkage between her father's status as a displaced immigrant and underdog within his own family, and his bullying and controlling behaviour towards Lyn and her mother:

"My father's family had this huge hang-up about darkness, and it always used to enrage my mother that the first question anyone asked when she had me was not what sex I was, or even if I was all right, but how dark I was. So the one member of the family in that generation who went to university was actually a girl, and she wasn't the oldest but she was the lightest and they put the money into her. So, my father was an immigrant and, as somebody not fitting into the Indian world when he'd been in India, or the English world, he had almost no status anywhere. And he did tend to dominate my mother and me, and was the classic bully, I suppose, in that it was the only place that he could, so tended to do it quite a lot. Understanding it doesn't necessarily mean condoning it, or feeling any better about it, but I can see where it might have come from. And he was the darkest in his family so he was very much the underdog amongst his brother and sisters, so he took it out where he could."

Lyn

Additionally, Lyn makes reference to the role reversal, chaotic functioning and the social isolation of her family:

"I have a very clear memory of about half a year later, looking at my parents and thinking, 'I have to look after them because they can't cope,' and that meant never complaining about anything."

Lyn

"It was just getting out of control in a very weird way, in the sense that it was very structured. The boundaries of it were very firm, the external boundaries, I mean: my mother literally never went out, my father barely had a social life, and my going in and out was pretty controlled. No children came to our house: I never invited anyone home partly because of my dad's drinking. By this point it was heavy enough for his behaviour to be erratic, and my mum's behaviour could be a bit erratic as well. It was just not something I did. Also, the

boundaries within the family were not quite as in other people's houses."

Lyn

When trying to make sense of her partial memories of sexual abuse occurring in the family context, Chloe also makes reference to the lack of familial boundaries, particularly sexual boundaries:

"And my family have actually been living with him (Chloe's grandfather) and tolerating this sort of behaviour and they think it's okay. Why, because my dad's behaviour is not quite right either. I remember my dad getting my mum wearing short skirts and talking about her knickers and talking about her being sexy. I didn't know that everybody's parents didn't do that."

Chloe

May refers to her stepfather's distorted belief system, which she believes provided him with a form of justification for his behaviour:

"I was first raped just after my sixteenth birthday, and I think he thought that this was not abuse because he was not a blood relative and also I was at the age of consent. I think he thought he was doing nothing wrong. I think that that was also why only touching happened up until that point."

May

All participants spoke about the relationship between their abuse and their impairment, expressing varying degrees of certainty relating to its contribution. In Thomas's case, he believes, emphatically, that his learning difficulties played a significant role in his selection for abuse by his stepfather:

"I do feel that my stepfather saw me as stupid and easy to target. He was always bragging about his intelligence and comparing my lack of intelligence to it. I definitely do feel this is why he targeted me and why I found it so difficult to stand up to him, unlike some of my older brothers."

Thomas

Jean also believes that she was targeted for abuse (sexual and physical) during her first period of hospitalisation. Below she describes her thoughts

about a process whereby impairment becomes a symbol of something inherently bad in the perpetrator's mind:

"But there is a really key issue here about recognising that disabled children, not only are vulnerable, but also are targeted in ways that non-disabled children are not. And I think that in some families the anger and the feelings about the impairment are going to get mixed up and be the reason why some children are targeted or used as an excuse for the abuse. I wasn't targeted in my family in that way but it was a similar kind of motivation going on within the institution."

Jean

".....the impaired body becomes a target, largely because it's a symbol of something else. For the nun who was abusing me, my impairment was a symbol of something else for her (probably Satan or evil). Because of our powerless position, and because such little value is given to our lives, abusers can get away with it, conceal it and justify it by dehumanising us – using terms like 'vegetable', for example. So I think there's a whole load of issues there about the body (including the mind) and about the body being the focus: being objectified and targeted because of the impairment or difference, and about others projecting symbolic ideas onto the impaired body – things like evil, ugliness, 'other', primitive, dirtiness, vulnerability, loss and death."

Jean

Lyn was sexually abused by a number of perpetrators as a child, including her father, strangers that she encountered in the park and, later, a friend of the family (Phil). As the sexual abuse experienced in the local park occurred prior to her hearing loss, it is clear that in these instances she was not targeted specifically because of her impairment. She also suggests that impairment did not play a part in her father's abusive behaviour. Later on, however, she chews over the idea again, in line with her own personal views about the sexual abuse of disabled children. In Phil's situation she is somewhat clearer, believing that she could possibly have been targeted because of her impairment but, equally, Phil could have observed her emotional availability:

"One of my ideas is that people are repelled by disabled children, and they are also slightly attracted by them because they are odd. It works both ways, that there's a sort of feeling of 'you can't damage them any more than they already are. You can't break them any more

because there's already something profoundly wrong with them,' so, somehow, it's morally less bad to do it. I'm sure that people would never say that aloud, or very rarely say that aloud, but I think there maybe something of that in it. He was punishing me for being defective, you know, I don't know. If I'd had siblings and I had been the only one, then that would have been clear. Phil, I think, could see that I was isolated and desperate for male attention. He may have been able to see the difficulties with communication that I had and been more sure that I wouldn't even think about talking about it. I still can't quite grasp this: he took a huge risk, I know that, in what he was doing, and somehow he felt safe enough to do it with me, and I'm not sure why that was and how much was what he observed and how much was the disability."

Lyn

Similarly, Chloe also makes a link between impairment and sexual abuse. She believes she was targeted because of her difficulties with memory, but also because of the consequences of a poor parent-child relationship, which resulted in a need to seek out attention from those willing to give it:

"In childhood I was vulnerable because they would have known that I was bad at remembering things, that I quickly move on from things and got on with it. They would have realised... because I spent a lot of time round at my friend's house, going on about my terrible relationship with my mother. So, again, it's the indirect stuff, it's not directly necessarily because I was disabled, but the consequences of being a young disabled person without the support that I needed for a variety of things that put me in a position of vulnerability, because I was needy, because I needed somewhere to get respect and support. I was really there for the taking for anybody that would give me the attention, you know. And a lot of it was to do with my impairment and it's to do with not having the support at home. My mother's relationship with my brother was fine so I have to see it as being about my impairment."

Chloe

This final set of quotes from Josh, May and Lizzie relate to the disabled child's impairment creating an increased opportunity for sexual abuse to occur. In Josh's situation, his need for personal assistance with intimate care tasks created the necessary cover for his stepfather's abusive activities:

"Also, I remember after that when we were still in the same house where the toilet and bathroom were downstairs, that occasionally I

would mess myself and he would use the opportunity of me having to have a bath, or having to clean me up, to abuse me. I was easily accessible; I was an easy target because of my disability. Because I had a disability, there was more opportunity to access me, and because I needed cleaning up in the bathroom, I was more available in the right places as well.”

Josh

A similar circumstance arose for May and below she describes a situation whereby the need for physiotherapy provided the opportunity for sexual abuse:

“I think once a disabled person is being abused it is easier for the abuser to find opportunities to be in close contact because of the need for support and things like physiotherapy, which then become used as excuses.”

May

When talking about her sexual abuse in hospital, Lizzie also refers to her availability, but in this instance it is alongside other non-disabled children who were available because of a requirement for medical intervention:

“And I must say that I have memories of other children on the ward being abused. I know it wasn’t just me, and most likely a significant proportion of them were not disabled, and that’s what I mean. We were a pool of available children and I was one of them and none of us could get away. How old the others were, I really don’t know, but we were a pool of available children in an era when it wasn’t even expected, or on the agenda, so I’m sure that he was very typical and that I was abused, not so much because I was disabled, but because I was available alongside other children. But that’s very individual, that’s very particular to me in a sense, it’s a particular circumstance and I’m sure other children, well, I know that other disabled children are targeted in situations in which they’re the only disabled children around, or they are the one child in the family who has been targeted. So there **are** disabled children who are targeted because they are disabled. I just don’t think I was.”

Lizzie

Bearing in mind that, in the majority of cases, the perpetrator’s predisposition to abuse a child was independent of the child’s impairment status, I think it necessary to begin with an overview of existing theoretical literature addressing the issue of why perpetrators sexually abuse children. Some, if not

all, of these theories will apply to perpetrators in this study. Later, I will focus on the specific issues that pertain to the disabled child's situation.

Models emphasising individual and family pathology have predominated early literature on sexual abuse with, more latterly, feminist analysis forcing a consideration of the wider social dimensions of the problem. Some of these earlier writings on intra-familial child sexual abuse use a family systems analysis and highlight the development of dysfunctional family relationships as playing the most significant part in the evolution of the problem (Mayer 1983). Similar to the descriptions offered by Lyn, these theories contend that it is the family's social isolation and enmeshed emotional relationships that erode inter-generational boundaries. Often marital discord and/or sexual incompatibility are cited as the reason for the child fulfilling the role of the mother, both emotionally and sexually. Despite the reality of some of these observations in clinical practice and, indeed, for several of the participants in this study, subsequent feminist critique has drawn attention to the inherent pathologisation of other family members present in these theories. This is particularly the case for the mother, who is seen to be partly responsible for the abuse, with the culpability of the perpetrator being somewhat diminished (Westcott and Cross, 1996).

Both the earlier writings of Miller (1984) and the more recent work of Marshall (2000) offer other models of individual pathologisation, which make the relational link between being sexually abused as a child and later becoming a perpetrator of abuse. Glaser et al. (2001), by contrast, highlights the discrepancies embodied within this proposed relationship.

Miller's theory (1984) is rooted in her own psychoanalytic practice, has more relevance to intra-familial abuse and evolves around the notion of repression and repetition. Here, child sexual abuse is repressed to ensure the child's survival, but at the same time it works to the detriment of the child's emotional well-being. Far from the repression process acting to keep a lid on the situation, the trauma becomes heightened, creating a need to articulate the experience by repetition compulsion, which becomes more urgent and

uncontrollable the more deeply repressed the original trauma. Although repetition compulsion can be seen in some individual's circumstances, and perhaps in Thomas's stepfather's case, the shortcomings of Miller's work relate, I believe, to the inevitability of this process, the lack of agency of the individual involved and the absence of any gender analysis.

Marshall's work (2000) is, perhaps, more applicable to extra-familial child sexual abuse and also offers a fairly detailed analysis of the process whereby a victim becomes an abuser. Drawing on both his own work and the work of Smallbone and McCabe (2003), which was unpublished at the time of writing, he makes the link between the poor quality of early attachment experienced by the abuser and the propensity to abuse later in life. He argues that an insecure attachment creates a child with low self-esteem, poor interpersonal skills and the desperate need for attention from adults. This, in turn, manufactures a vulnerability that increases the risk of being sexually abused. The possibility that some sexual pleasure is derived from the experience may result in the child perceiving the experience in positive, non-harmful terms, so removing one significant barrier to sexually offending later in life.

Some of these theories may, or may not, have some relevance to the perpetrators in Lyn's and Chloe's experience of extra-familial abuse. It is limited in the same way that Miller's theory is, because poor attachment in early childhood does not necessarily result in sexual victimisation, followed by the perpetration of sexual offences against children.

Glaser et al. (2001) undertook a large-scale study investigating this proposed "cycle of child abuse." Using a method of clinical case note review, they found no significant relationship between poor early attachment patterns and subsequently becoming a perpetrator. In conclusion to their study, Glaser et al. contend that being a victim of child sexual abuse is just one factor contributing to an individual becoming a perpetrator, and that the "cycle of sexual abuse" is essentially tied to a special sub-group of clinical forensic psychotherapy patients. It is not representative of the wider population of victims and perpetrators. They also acknowledge the possibility of

perpetrators, in their study, pretending to be a victim in order to get preferential treatment or therapy.

Although recognising that an understanding of perpetrator psychology is necessary in clinical practice, and in opposition to approaches that focus on individual psychopathology, radical feminists offer a valuable and, in my view, a very relevant social analysis of child sexual abuse. They theorise it as being just one form of violence experienced by women and children in oppressive family institutions, a fact that is backed up by others clinical research (Dong et al., 2003). This atmosphere of violence was certainly apparent for some survivors in my research and was particularly evident for Thomas.

Solomon (1992) believes that, within the family, men are socialised to dominate women and women are socialised to be compliant, with the system perpetuating itself by the production of children with the same attitudes. Family dynamics, according to Walby (1990), mirror the power dimensions of the wider patriarchal social structure, where men are validated by their machismo, sexual success is imperative for gender identity and violence is sanctioned as a legitimate method of men obtaining what they want. She believes that the eulogising of violence is epitomised in an army existence where many young men can spend a notable period of time. I believe a radical feminist analysis of sexual abuse is highly applicable for many participants in this study, and I think that it may not be a coincidence that six of the ten perpetrators had spent variable periods of time in the armed forces.

Solomon (1992) argues that the relevance of a patriarchal analysis of child sexual abuse is best observed when considering her and other's prevalence data, which demonstrates, overwhelmingly, that perpetrators are usually male and girls are usually, but not always, the victim. When women do abuse they often abuse female children and generally have male instigators or accomplices. Glaser and Frosh (1988) believe that it is the "normative factors in the socialisation of men" that account for the fact that the sexual abuse of children is so common. In fact, other authors, such as Solomon (1992), link the social acceptability of sexual abuse and the heterosexual adult male

preference for smaller and younger sexual objects. Additionally, other writers, as indicated earlier (Chapter One, pages 18-19), draw parallels with the sexualised depiction of children in advertising and the relatively free availability of child pornography, both of which provide affirmation of the appropriateness of conceptualising children in sexual terms.

Finkelhor (1984, 1986), clinician and writer, was perhaps the first author to attempt to provide a model, which combined both the individual and social aspects of perpetrator behaviour. His model cites four preconditions for abuse, which include firstly, the individual having a motivation to offend, such as the re-enactment of childhood trauma. Secondly, he cites the individual as needing to overcome any internal inhibitors, by believing in the patriarchal privilege of fathers, for example. Thirdly, he believes the individual has to overcome the external inhibitors, such as support from social and familial networks and lastly, the individual needs to deal with any resistance that the child might present. As far as Finkelhor is concerned, a range of social, cultural, developmental and psychological features need to interact to produce a perpetrator profile, with no single factor on its own leading to a man sexually molesting a child. This holistic perspective is currently used in some therapeutic group work models with offenders, where attempts are made to place the behaviour of the perpetrator in a broader social context (Lancaster and Lumb, 1999).

In relation to the sexual abuse of disabled children, Shakespeare (1996a) lists a set of factors, including: institutionalisation, dependency, communication and invasion of privacy, which he believes increases disabled children's vulnerability to abuse. By listing these factors, it needs to be stressed that there is no attempt, here, to invest any culpability with the disabled child. As already discussed, these factors are socially constructed by a society that relegates the needs of disabled individuals.

For those disabled children who require personal care, such as May and Josh, their situation becomes complicated by a dependence on informal carers (Shakespeare, 2000a), some of whom turn out to be perpetrators, and

who are then provided with the necessary opportunity to sexually abuse. Sobsey (1994) makes the point that in this type of “caring” relationship, where the disabled individual is physically very dependant on the abusive caregiver, as was the case for Josh, May, Lizzie and Jean, there may be very little choice but to comply with the abuse. In Chloe’s and Lyn’s situation, their impairments created particular communication difficulties, related to memory and hearing loss, which potentially provided another source of opportunity for a paedophile. Both of these individuals felt that their home circumstances, which included intra-familial sexual abuse and/or difficult parental relationships, also created an emotional availability that increased their risk of extra-familial abuse. This issue will be discussed in more detail later on in this chapter.

As already indicated, perpetrators of child sexual abuse can be shown to demonstrate distorted belief systems, which act as justifications for their behaviour (Miller, 1983; Finkelhor and Araj, 1986; Marshall 2000). This can include a belief that the sexual abuse of a stepdaughter, as in May’s case, is permissible. For disabled children, Shakespeare (1996a) and Westcott and Cross (1996) argue that perpetrators can use a range of distorted assumptions and justifications, such as a belief that disabled children are destined not to have sexual relations and that any sexual contact is better than none. These justifications may also include those expressed by Lyn, whereby the additional damage caused by sexual abuse is seen as negligible, since the person is significantly damaged already.

Shakespeare (1997) also identifies a wider social issue, which may be more relevant to the abuse experienced by Thomas and Jean, and centres on the fear and hate that non-disabled people can hold for disabled people. This fear and hate, Shakespeare (1997) contends, relates to the meaning attached to impairment in western cultures. He argues that disabled people can symbolise a passivity and weakness for non-disabled people, which, in turn, creates a fear and loathing. Unable to contend with their own feelings concerning their personal vulnerability and the fragility of life, non-disabled people project this

fear onto those who represent weakness and who generate this insecurity in the first instance (Chapter One, page 14).

In terms of distorted belief systems, and in the context of exploring the origins of oppression in disabled people's lives, Barnes (1996) plots a historical process whereby a relationship has been made, within Christianity, between impairment and the devil. He asserts that the church has retained its authority throughout time by perpetuating a fear of the devil and that a biblical link has been made between impairment, impurity and sin, with disabled children being seen as the "devil's substitute for human children." Douglas (1966) argues that one of the major doctrines of Christianity is embodied in the book of Leviticus, which equates holiness, a quality that all individuals should strive towards, with wholeness or completeness. Douglas writes that much of Leviticus is focussed on the need for physical perfection in those meeting God in the temple. She writes that "animals offered in sacrifice should be without blemish, women should be purified after childbirth and lepers (the physically impaired) should be separated and ritually cleansed."

I think it is safe to offer some parallels here between the writings of Barnes (1996) and Douglas (1966) and the ritual cleansing abuses experienced by Jean in her first period of hospitalisation i.e. the nun was attempting to cleanse Jean and exorcise the devil. Paradoxically, however, other behaviours exhibited by this nun, such as attempts to make Jean ingest faeces and the near-drowning episodes, are also reflective of some of the satanic worshipping rituals referred to in the research of Saradjian and Hanks (1996).

ii) Understanding perpetrator tactics: "I will batter you to a pulp to get what I want"

In addition to the power differential created by chronological age, other methods used by perpetrators to gain and maintain control of their victims varied. These ranged from overt demonstrations of aggression and brutality, subtler methods of "courtship" designed to create feelings of complicity in the

victim, the creation of confusion and ambiguity in the child's mind and the use of organised networks. In Thomas's case, his stepfather's aggressive behaviour, both during the act of sexual abuse and at other times, created feelings of immense fear and left him in no doubt about the wisdom of sharing his experience with anyone:

"Sexual abuse is evil, full stop; you can't say, well, some sexual abuse is mild and some very unpleasant. It is awful, and when it's forced upon you, that's what makes it worse, and his was a complete brutality. There was no 'Okay, you've begged me enough, I'll stop,' it was, 'I will physically kick you to death to get what I want, I will batter you to a pulp to get what I want. You will be compliant, you will do as I say.' "

Thomas

"...he used to insist on bathing me, and they had to be salt baths (following an operation). And I can remember him once getting this towel and dropping it in the water, and I thought, 'what the hell are you dropping that for?' and then he got it out and says, 'Watch this,' and he wrung it out and goes, 'I'll show you a trick.' He wrapped it completely around my face and I'm like, 'ugh.' I couldn't breathe and I was just blacking out when he took it off, slapped me and brought me to, and then did it again. I used to have a lot of flash backs about that, a hell of a lot."

Thomas

For Josh, who began to equate his abuse with punishment for soiling himself, an empty choice was given as to whether he wanted to be physically beaten or sexually abused. Here he elaborates further:

"And I got told, 'Well look, you've got two choices. You can either go straight to bed now (for sex),' and this was sometimes at five o'clock in the afternoon, 'or you can have the belt.' So, I mean, what sort of choice is that for somebody when there is a body function and you're not always in control of it? And I'd say, 'Okay then, beat me because I'm not giving in.' He'd beat me and then, quite often, I'd get abused as well. So apart from the physical abuse, I'd get sexually abused as well."

Josh

Lyn's sexual abuse by her father did not assume the same overtly aggressive characteristics of Thomas and Josh's abuse. It was marked, however, by the

confusion that it created for Lyn, since it often happened in public and was witnessed by a number of people who chose not to intervene in the situation. These individuals have since confirmed their feelings of disquiet about her father's behaviour. Below, Lyn describes her feelings about the experience and its consequential effects:

"The stuff that I read about when I was in my 20's, as I was trying to make sense of it, never fitted that pattern. The stuff about it being very secretive, about you being daddy's special little girl, about this being our big secret, and threats, that kind of thing never happened. It was much more a sort of possessiveness in front of other people, which went much too far. And what was so disorientating about it was that other people saw it but didn't do anything. It was like he was flaunting his ability to control me, to do what he liked. The most minimal thing was stuff like grabbing my breast and putting his hand between my legs, but always in public, nearly always in public. The furthest I remember him going was digital penetration but, again, done in public, at least sometimes. And I'm fully aware how bizarre it sounds, but picking me up between the legs and one of his fingers 'accidentally' getting inside."

Lyn

"I can't put myself in the position of somebody where it's all happened in secrecy and with coercion. What I can say is that this was just as damaging because it was intensely confusing. It meant that because it was happening in front of other people it was all right, but I also knew that it wasn't all right, so there seemed to be some different sets of rules."

Lyn

Lyn's sexual abuse by her father stopped when she was approximately twelve years old. Then she became involved in an abusive relationship with one of her father's friends, which started with "grooming" type behaviour, probably designed to test Lyn's capacity to resist his sexual advances. It involved creating a sense of equity, even collusion, in the relationship:

"But at the time, he, Phil, was saying things like I was much older for my age than other girls. I was flattered by the maturity he was implying and I was flattered by his attention, and I was getting attention from him that I wasn't getting from my dad. It started with those jokes that are slightly edgy and then discussions about boyfriends, and then touching and stroking, and then step-by-step,

over a period of probably weeks, or maybe it was days, but I think weeks.....”

Lyn

“I don’t remember, at the time, feeling that I was being exploited. I thought I was an equal partner, or even in control. I think from things that I remember him saying, that I have discussed now with my therapist, he either instinctively or consciously manipulated that to happen. On a few occasions, I remember when he got excited, when he got an erection, he said to me, ‘Now look what you have done.’ And it was half joking. And with equal partners it would have been a joke, you know, play, but because we weren’t equal partners, it wasn’t. And there was a part of me that felt, ‘yes, that’s something that I’ve done.’ “

Lyn

“For me, the kind of thing that happened to me is damaging in a corrupting kind of way. You feel so implicit in it; you feel that your edges aren’t straight any more. I really don’t want to say that there are some children who are assaulted who get off easier, that’s not what I am trying to say. Their moral boundaries may remain the same because they know that what happened was very wrong and that maybe they had nothing to do with it. Where you have been put in a position, perhaps deliberately, by somebody else in which it feels like you are the one who is making all the moves, and you’re the one who is in control, and you’re the one who is making it happen, it’s just corrosive in terms of redoing it afterwards. I’m only just beginning to see how hard that is to undo.”

Lyn

Chloe, who was sexually abused as part of a paedophile ring, talks about some of the methods used by her perpetrator:

“A friend of mine did some ‘grooming’ for some people. I knew she was friendly with these people that lived near her and that she babysat, and I vaguely remember that there was something dodgy going on but I can’t remember what. I think it was all a bit, not really being said. I got asked to go and baby-sit for these people and I went round on my own to these people’s house. They gave me a few drinks and off they went out, and I don’t remember any kids being there. It’s a funny thing, I just don’t know if the kids were there or not, I really can’t remember. Anyway, because what I do remember is so significant, little facts like that are just... Anyway, later, somebody came round and it’s so...even at the time it was obvious to me that it was organised, I think I knew he might come. What I didn’t realise at

the time was that it was abuse, I didn't realise that it was wrong and, also, I wasn't capable of saying no."

Chloe

"The police said that sometimes people like that will use drugs on children as well. He said (the policeman), 'Are you aware that you might have had any drugs,' and I honestly don't know. Because for ages I couldn't work out why I couldn't remember what happened next, and it was only when I came to give my statement, I realised I must have been unconscious."

Chloe

In this section I review some of the literature that relate to the methods used by perpetrators to achieve their intended goal. As a result of interviews with 23 perpetrators (20 male and three female), Gilgun (1994) constructed a typology of sex offender behaviour, which lay on a continuum, but was marked by its fluidity and the way that abusers moved between categories over time. Typologies included: 'avengers', 'takers', 'controllers', 'conquerors', 'playmates', 'lovers' and 'soul mates'. Thomas and Josh's abusers clearly fit the category of, what Gilgun describes as, 'takers.' These are perpetrators that see the child as a commodity to be used and then discarded, with little regard to the consequences of their actions. In Josh's case, perhaps one of the more corrosive dimensions of the experience was the association that was being made, in his mind, between impairment, punishment and abuse, in a situation where he had no control.

These perpetrators (takers) often use violence and force, and the abuse generally results in rape. To a certain extent, the paedophile that abused Chloe also fits this typology, by using alcohol and drugs to get what they wanted. Lyn's abuse by a paedophile operating close to, but outside, the family fits both the categories of the 'playmate' and 'lover.' Sex was just one activity that the perpetrator involved Lyn in, and his comments about Lyn's age signalled a distorted belief system and an illusion that there was a degree of equity in their relationship. Lyn's abuse by her father does not easily fit any of Gilgun's categories. However, it has equally had a destructive impact in terms of interfering with Lyn's "moral referential system," which informs

decisions about what types of behaviour (in others) can be classified as appropriate and inappropriate.

Similarly Gold et al. (1998), by using a survey of 165 women in outpatient therapy, also constructed a typology differentiated in terms of how the perpetrator abused their power and the manner of coercive control that was involved. Their categorisation included compliance, which required a high degree of victim involvement, subjugation, which involved acts that take place without compliance, and objectification, which involved penetration and treating the victim as an object rather than a person. Applying this typology to my research sample also necessitates a degree of overlap within these categories. Thomas's experiences, for example, would fit both the subjugation and objectification categories. The shortcomings of both Gilgun and Gold's work, in my opinion, relates to the absence of analysis related to the trauma, which results from these behaviours.

Researchers such as Russell (1986), on the other hand, group sexual acts according to severity, making assumptions that the level of severity equates with effect. She proposes that penetrative activities create the greatest trauma for the victim. Niederberger (2002), using questionnaire and interview methodologies with victims of abuse, has also looked at abuse typology and effect, but here investigated abuse-specific variables, which were decisive in determining the severity of effect. His findings challenge an assumption that the use of force, such as was present in Thomas and Josh's case, worsens the outcome for victims. He found that strategies involving affection, such as the tactics used by Lyn's family friend, had a stronger effect since they had an increased self-blaming implication. Equally, but to a lesser degree, he found that victims struggled to reconcile abuse tolerated for a prolonged period of time. By way of methodological bias, he acknowledged the fact that the participants who had experienced force had not experienced the extremes of force prevalent in some studies. Nevertheless, he found a correlation between the use of force and subsequent anxiety, with a fear of punishment relating to lack of compliance, as in Thomas and Josh's case, ultimately creating depression.

Any typology of sexual abuse can equally apply to perpetrators acting alone, or to perpetrators acting as part of an organised network, as was Chloe's experience. Having said that, however, I think it is important to flag up some of the issues pertinent to this type of organised practice. Wyre (2000), who has worked extensively with perpetrators, describes perpetrators that act outside the family as "fixated paedophiles." He differentiates between predatory paedophiles, who typically abduct to offend, and non-predatory paedophiles, who believe that children enjoy sex and are able to give consent. Using Wyre's classification, both Chloe and Lyn were abused by non-predatory, fixated paedophiles. Wyre (2000) describes the typical characteristics of a fixated paedophile, which may include contacting other paedophiles who validate their beliefs and with whom they share information about vulnerable children.

Organised child sexual abuse is notable by the difficulty created in its detection. It often involves large numbers of children who may be drawn from specific neighbourhoods or estates. Gallagher (1998) asserts that, frequently, these children demonstrate a group characteristic of resistance to impregnation by officialdom. Victims may be recruited by other children on behalf of the abuser, as was suspected by Chloe, and may be "tied in" by the inducements, offered by the paedophile. These inducements, Gallagher writes, may include things like sweets, toys, money, alcohol and drugs. They may also include attention and affection that the child lacks in other parts of their life; issues also alluded to by Chloe.

Additionally, these paedophiles employ strategies to throw officials off the scent, including: the intimidation of witnesses, or the removal or destruction of evidence. From his work with paedophiles, Wyre (2000) comments that often paedophile's strategies are fine-tuned in prison by contact with other paedophiles, who they may end up working with on their release.

c. Narratives of childhood: “the double whammy effect”

Within this section I will be exploring the position of the sexually abused disabled child, who endeavours to make sense of their experience and is often at the receiving end of an amalgamation of disadvantage created by both disability oppression and child abuse; a situation which Josh describes as the “double whammy” effect:

“I think there are particular issues for disabled people who are sexually abused. Sexual abuse for any child is absolutely appalling but it’s worse in the respect that the disabled kid, whatever the disability is, whether it’s learning disability or physical disability, it’s worse in the respect that you’re already at a disadvantage, you’re already coping with lots of extras. Like I can’t use my arm, I couldn’t do up my buttons, I couldn’t wipe my arse, I couldn’t do this, I couldn’t do that, and then somebody comes along and abuses you, sexually as well. So that’s also taking something else away from you, so I think it’s like having a double whammy; you know, you’re hit once with your disability, you have to cope with non-disabled kids staring at the effects of your disability, then to get that on top, you’re being hit twice.”

Josh

When trying to sum up the feelings engendered in the child by the experience of sexual abuse, both Thomas and Lyn describe the creation of a sense of powerlessness and worthlessness. These emotions typified the feelings of all of the participants in this study and are also shared by many non-disabled survivors:

“Later that evening, when I was in bed, he came into my bedroom and beat me up. He told me there was no point in telling my mother because she wouldn’t believe me and that if I opened my mouth I would end up in the children’s home that his mate ran, and that he would really make me scream. I heard him leave and go downstairs, laughing to himself. It was a laugh of arrogance, of one-up-man ship. He had got away with it, convinced my mum so she believed him and lost me my milk (a drink I loved but cannot touch today without being physically sick). I remember laying in bed feeling useless, worthless, and knowing that he had all the power in the world to do what he wanted with me. I was totally beaten.”

Thomas

"A couple of years ago a film came out called 'Festen', which means the celebration or the party. It's a Danish film and it's about a father's 60th birthday party at which one of his children makes the revelation that he has abused them as children. It's almost comical in some places because it's so awful. It's deliberately, blackly comic, but it's also very painful. Anyway, I saw it with a group of people and one of the other people that I know had been abused - he is open about the fact that he's been abused by his father. There's this tiny bit of dialogue in the film where the son, who is actually by now very drunk, says in front of a lot of other people, 'I just want to know why it was. I never understood why you did it,' and the father was in a rage and storms out of the room and almost in passing says, 'it was all you were good for.' When that happened, I remember that I looked across at this guy and he looked at me, and we both knew."

Lyn

For all of the participants in this study, additional disability related issues were added to the difficulties that most sexually abused children have to contend with. At the beginning of this section Josh describes the impairment related challenges faced outside the family home. Below, both May and Lyn talk about the difficulties experienced within their immediate family environment, where they felt that they were perceived by their parents as "burdens" or "problems." They later cite this as one of the factors that contributed to their inability to speak out about their abuse experience. I start with May's words:

"My father felt that I had a disease and would have nothing to do with me. He also had a number of affairs just to prove that there was nothing wrong with him. So all this resulted in my mother leaving him, taking my younger sibling and me with her. From about the age of four I can remember being told constantly, by my mother, that she could have stayed and had everything that she wanted, but instead left because of me. This made me feel like I had wrecked my mother and sibling's life."

May

"I don't think that there was ever a chance that I would have told because of my feelings of having to make up for breaking up the family the first time round. For years I had been told I was an inconvenience, and that having someone with a disability in the house meant you couldn't do things. I was told that they couldn't have the holidays they wanted, they had to buy things they wouldn't buy normally, or replace things more often. These things just made me

feel I was a nuisance, not good enough, and that I should support the family because I was costing them money. I came close to telling once or twice but just could not face the consequences of doing it. I thought my mother would hate me even more and I thought I would lose contact with my youngest sibling who I am very close to."

May

Here Lyn expresses her thoughts and feelings on the subject:

"..... you just feel apologetic the whole time within your family and in the rest of the world. You are a trouble and a problem and, however accommodating the environment, the accommodation has to be made, and you see it being made and you don't want to cause trouble. It becomes ingrained and, certainly, my mother's training had been, and what she handed on to me was, it must not show, you must not do anything which draws attention to yourself."

Lyn

"Social services were still coming to the house at that time but I couldn't tell because I still couldn't articulate what was wrong. All that I could have said was that there was something wrong and a large part of that was the feeling that it was me that was wrong."

Lyn

In this next quote Lyn describes a complex set of emotions whereby being perceived as a problem later translated itself, in her mind, into feeling that she deserved to be sexually abused. This, again, set up the impairment-punishment-abuse association, and also later translated itself into a sense of pride, in that it was something she could deal with:

"The reverse of that is the feeling that you actually deserve it, really. If anybody deserves it in the family, you do. It's absorbing the problems. I used to have this fantasy that I was a sponge, and actually absorbing things like that (being sexually abused), becomes a good thing to do, it becomes your role. The many things that you can't do that other children can do in their families, e.g. being musical, or if you are in a wheelchair, being athletic, but you are able to do this! One thing that I did say to my therapist a while ago was that in all this time, between age eight and age fourteen, although there was a sense in which I didn't acknowledge that there was anything wrong, I also knew that there was a girl at my school called Jeanette, who everybody knew was being abused by her father. Everybody knew it. She was a wreck, and the awful thing is I can remember feeling

contemptuous of her because she couldn't hack it, she couldn't handle it. There was pride there, there was the feeling of 'for Christ sake, I'm deaf and I can do it, and you're normal and you can't.' "

Lyn

Both May and Chloe comment on other consequences of disability for their relationship with their parents. In May's situation, she believes these difficulties resulted in her placement at a "special school," which took her away from home, for a number of years, when she was still quite young. She relates the lack of a parental bond to her vulnerability to sexual abuse within the family. In Chloe's case, she talks about the stress that an undiagnosed impairment placed on the parent-child relationship, which was made more difficult by her mother's lack of support systems and her geographical isolation:

"I know I do not have the same bond with my parents as my siblings. I think this is because boarding school is an environment where you are expected to be self-reliant as much as possible, both physically and emotionally. I think the lack of shared experiences also contributes, as you have your experiences from school, and your family have their experiences at home. I think the resulting lack of bond may make it easier to abuse a disabled child in the family setting."

May

"My memories of when she talked about me as a baby, were just of me being a problem. She was bringing me to the doctors because of my behaviour, because I was very demanding. It was because I had ADD. I know now what it was."

Chloe

"I realise now that my mum probably did have depression, but was also having a hard time. She had a disabled child, actually, who wasn't understood by anybody else, or her, and no one to help her with it. And she was on her own in a foreign country, pregnant and then with a second baby, you know, she had a lot of stuff to deal with."

Chloe

In contrast to all of these narrative episodes, Lizzie describes her parent's reaction to her impairment at birth, and their continuing support of her whilst she was growing up:

"When I was born, my mum just totally accepted me instantly and the nurses were really surprised. They said to her, 'most women ask, has the baby got ten fingers and ten toes, and you didn't,' and my mum was just a hundred percent accepting of me, and my dad as well. So that was an enormous pillar of strength for me. And they did fight for me when fights were needed, as many of our parents do."

Lizzie

The sense of powerlessness and worthlessness created by the experience of being sexually abused, and described by both Thomas and Lyn, is also illustrated in the narratives of many non-disabled adult survivors (Ward, 1984; Fraser, 1987; Pearce, 2000; Edwards, 2000; Durham, 2003). So too has the consequential emotional effect of that powerlessness (Gale et al. 1988; Rimsza et al. 1988; Mian et al 1996). Some writers have stressed age and gender variables; showing that adolescents display more acute psychological distress than younger children, and girls showing more of a propensity to internalised symptomology than boys (Feiring et al., 1999). Other authors have stressed the impact of emotional distress on the physical body, with Dong et al. (2003) highlighting the effect of trauma, such as child sexual abuse, on the developing brain. The emotional consequences of child sexual abuse, which will be discussed further in the next chapter on identity, are similar for disabled and non-disabled children. But disabled children, as already indicated, have extra disability related issues to deal with, which then become entangled with the sexual abuse. It is to these issues that I now intend to turn.

In addition to the prejudices mentioned by Josh, and as experienced by disabled children in their general encounters in their social environment, the issue implicit in other participant's narrative episodes of family life, is the notion of the disabled child as a "problem" or a "burden." Dissimilar to Lizzie's parent's reaction, Middleton (1992) contends that these "burden constructs" often mark the birth of disabled children, so symbolising the first

experience of social devaluation for that individual. Frequently, the event is surrounded by a sense of misfortune and the loss of the “perfect child” (Ablon, 1990), an issue referred to by Jean in Chapter Four (pages 146-147). Notwithstanding the actual difficulties for parents in accommodating the child’s impairment into their emotional world, and the medical implications of that impairment, the medical profession can sometimes be seen to collude in the social devaluation of the child by perpetuating a notion of “tragedy.” Tragedy discourse frequently prevails in subsequent visits to health settings (Avery, 1999) and often carries over into the family’s subsequent encounters in public places, where the reactions of strangers reinforce the message (Green, 2003).

Green (2003) offers some interesting observations on the dynamics at play when mothers bring their disabled child into public places. Her work is based on qualitative research methodology, involving a survey of 81 mothers of physically impaired children, and in-depth interviews with eight of those mothers. Green works with the concept of “courtesy stigma,” a concept derived from the writings of Goffman (1963) and which examines the impact on the mother of other’s reaction to their disabled child.

As well as illustrating the emotionally burdensome effects of constantly having to contend with the management of others’ reactions, Green’s work draws attention to a number of other important findings. The interviews demonstrate that mothers often come to the parenting experience with some of the same stigmatising attitudes towards disabled people as the majority of society, an issue, which is alluded to in one of Lyn’s quotes. As was prevalent for both May and Lyn, Green found that this oppression had the potential to result in an increase in the perceived burden of caring. It resulted, for the mothers in Green’s study, in them reducing their contact with the outside world and also decreasing the frequency that their disabled child interacted with non-disabled peers.

Managing their own and others’ reactions to their child is just one of the challenges facing the parents of disabled children. Other potential difficulties

highlighted by other research include the impact on familial relationships, particularly the parental relationship, which may come under a great degree of pressure (Hornby, 1992). This issue is clearly visible in May's experience where the parental relationship did not survive.

Snell and Rosen (1997) identify some of the pertinent factors that enable parents to facilitate a positive family experience for their disabled child. These factors include the family sharing a common set of values, which influence how family members view impairment. It also includes an ability to create meaning from their situation, with the effect of positively constructing the disabled child's presence within the family.

Another significant issue is the ability of the parents to "weed out" unhelpful members of their support system; so facilitating a structure which provides both positive practical and emotional input. From what can be ascertained, a number of the families in this study, for varying reasons, including internalised oppression (Reeve, 2002), were unable to achieve these ideals. Others, in the case of parents of children with hidden impairments, were unaware of the root cause of their difficulty. Both Snell and Rosen (1997) and Hornby (1992) also comment on one of the other major positive consequences of being a parent of a disabled child: the personal growth and existential shift in what they consider to be important in life.

Thomas's research (1998) approaches the issue of parenting from the perspective of the disabled child, by obtaining the views of 68 disabled women on their experiences of childhood. Whilst acknowledging, for parents, the effects of dealing with a disabling environment, respondents told stories of parents that ranged from supportive allies to obstacles to psychological well-being. Some of the undermining issues that Thomas's participants had to deal with are listed below; a number of which were also common to the experiences of respondents in my study:

- Father's blaming mothers for the child's impairment (page 102).
- Fathers resisting any physical contact with the disabled child.
- The disabled child emotionally supporting the mother in her inability to deal with her child's impairment and her relationship difficulties.
- The child's fear of abandonment (page 102-103)
- Parents denying the child's emotional needs (page 84).
- The child's isolation (page 78).

One of the early consequences of a process whereby a child is perceived as a burden can be its impact on the parent-child attachment. Bowlby (1951) is perhaps the most well known writer on attachment theory. He stresses the importance of a warm, affectionate and secure attachment for the healthy psychological development of an infant. Bowlby highlights the centrality of the mother in the attachment process, with later authors, such as Rutter (1972), questioning the necessity for the primary caretaker to be the mother.

Within contemporary psychiatry, there is a general consensus that there exists four types of attachment patterns: the secure attachment, the avoidant attachment, the ambivalent attachment and the disorganised attachment (Marshall, 2000). Clearly, the secure attachment is considered to be the ideal, where the child sees the caregiver as a secure base that can assist in the "working through" of anxiety and distress when such stressful situations present themselves for the child. The secure attachment also allows the child to later separate from the attachment figure and concentrate their efforts on their wider environment.

When the attachment process is interfered with, through the direct or indirect influence of disability, for instance, there is the potential for destructive repercussions. Both May and Chloe spoke about problematic attachments, which they described as having different causes. In May's case, she makes the link between residential education at an early age and a poor parent-child

bond. Chloe's issue relates to the lack of support systems available to parents of children with hidden impairments. Muris and Maas's research (2004) attempts to look at the relationship between attachment styles, disability and institutionalisation, finding that children who are institutionalised show an increased evidence of avoidant and ambivalent attachments. Despite its limitations, this study did not show that institutionalisation creates insecure attachments, per se, since a significant percentage of the children who were institutionalised came from difficult family backgrounds. What this research does indicate is that insecurely attached children are more likely to be institutionalised, which in turn intensifies the process, so creating higher levels of difficulty for the child later in life.

The results of this particular piece of research may be reflective of May's situation, where family difficulties prevailed before she went to residential school. However, for May, it is clear that the process of institutionalisation created a sense of distance, in her mind, between herself and the family. Chloe's situation reflects a wider social issue, where parents of children with hidden impairments fail to receive the professional support they require (Read, 2000). This can then result, as in Chloe's case, in negative consequences for the parent-child relationship.

The relationship between attachment and childhood sexual abuse gained increased academic exposure in the 1990s, by providing another perspective on the problem of sexual abuse. Bolen (2002) examines some of the central tenets of attachment theory and its relevance to child sexual abuse, providing supporting research literature, of varying reliability, along the way. Although previously referred to (page 87), the major issue discussed, which may be of some relevance here, includes the behavioural manifestations of insecurely attached children. This can involve a propensity towards clingy and dependent behaviour; creating an increased risk of sexual abuse outside the family. This issue may have some resonance for both Lyn and Chloe. The repercussions of an insecure attachment can also be found to affect the likelihood of the sexually abused child to disclose sexual abuse and to receive

the appropriate support from the non-offending parent, an issue detailed by May, but which might have some relevance for other participants.

A problematic attachment certainly impacts upon identity formation, as will become apparent in Chapter Four. It can also produce distorted belief systems, which, in Lyn's case, involved the child believing that they deserved to be sexually abused. As already indicated, this pattern of thinking, again, sets up a relational link between impairment, punishment and abuse, but in Lyn's case with the addition of pride; relating to her coping ability.

In conclusion of this section, I will return to the work of Thomas (1998), who stresses the role that parents play in the disabled child's perception of themselves and their subsequent identity formation. As a tool of empowerment, she advocates the use of the social model of disability by allied professionals in order to help parents and their children re-interpret impairment in less negative terms. By building on positive interpretations of impairment, and securing strong parent-child attachments, parents, with the right type of assistance, I believe, can provide children with vital self-endorsement. This can increase their confidence when dealing with their disabling environment and has the potential to play some small part in their later protection from perpetrators. This theme of attachment will be taken up again in the next chapter, where the subject's relevance to identity formation will be developed further.

d. Concluding remarks

Within this chapter I have demonstrated that the sexually abused disabled child is potentially located at a collision point of a number of oppressive societal beliefs and practices, related to the treatment of both children and disabled individuals (Chapter One, page 15-19). These beliefs and practices manifest themselves in a societal ambivalence towards the subject of child sexual abuse, generally. They also produce the discriminatory treatment of

disabled people, which then influences society's capacity to deal with the problem of sexual abuse of disabled children in wholly effective way.

The research illustrates how the oppressive attitudes relating to impairment can impregnate the cultures of certain organisations, reproducing themselves by the recruitment of like-minded employees (Salaman 1979) and the creation of abusive environments. Participants' experiences of the medical profession, for example, involved prolonged periods of hospitalisation for two participants, which resulted in both physical and sexual abuse, and the witnessing of infanticide. Equally as distressing, participants referred to the aggressive administration of medical treatments and the general objectification of their impaired bodies, with linkage being made between this latter experience and the potential for later victimisation.

Similarly, participants' experiences of educational systems were also problematic. For those participants who experienced residential education, their narrative contained examples of sexual abuse by another child resident, the failure of the organisation to provide appropriate levels of education and a socialisation into compliant behaviour. Mainstream school also offered a number of challenges created by an educational system that failed to understand and promote an inclusive ideology. For those adult children who were clearly illustrating signs of anguish, relating to their abuse experience, professionals consistently failed to respond appropriately to their distress signals. Participants also spoke of difficult encounters with their local authority, which resulted in a failure to receive more focused support services, which might have prompted earlier disclosure or facilitated an earlier escape from an abusive family environment.

Equally, some of the same attitudes towards disabled children were shown to infiltrate family life, creating a conviction for some men that they held ultimate power within the family system. Physical violence and sexual violation were just one manifestation of patriarchal power, with impairment creating an increased opportunity for sexually abusive incidents to occur. Similarly, impairment was also seen to provide the necessary justification for perpetrator

behaviour. For some individuals in this study, negative attitudes towards impairment affected the general quality of parenting they received, influencing, amongst other things, their perception of themselves as “burdens” or “problems” and influencing their ability to subsequently disclose their sexual abuse. Ultimately, sexual abuse created feelings of powerlessness and, for others, exacerbated feelings of worthlessness (pages 101-102).

Having considered the issue of power in some detail, I shall now move on in the next chapter to explore how these abuses of power manifested themselves for disabled children and adults in terms of their identity formation.

CHAPTER FOUR: NARRATIVES OF IDENTITY

Within this chapter I will be exploring the combined impact of disability and child sexual abuse on participant's identity formation and identity enactment. I will also address its relativity to the creation of a sense of "selfhood" in both individual and collective terms, at different points in their lives. I will be arguing that a variable and sometimes fragile sense of self created by negative attitudes towards impairment in early childhood, is fragmented by the experience of child sexual abuse, so creating a series of dissociative behaviours and, for some, confused sexual identities, which persist into adulthood effecting both an individual's relationship with the self and with others. I contend that the reintegration of mind and body in adulthood, a process which may be influenced by impairment, is influential in terms of the ability to form a positive sense of self, rewarding relationships with others and sometimes empowering collective identities in a wider society.

I will commence with consideration of the individual's thoughts on their collective identity, which they may share with others who have had similar experiences and/or share similar beliefs. Arriving at a personal ownership of these collective identities, which mostly exercise their power through providing affirmation of the self, signifies, for many participants, a point at which they have been able to become re-united with their sense of self and reclaim some of what had been stolen from them in childhood. Working backwards, chronologically, I will then consider the position of the sexually abused disabled child who because of their abuse and perceived dangers of their environment has had to employ a plethora of behaviours, designed to protect their selfhood, which then become seen, by themselves and others, as part of their identity. I finish the chapter with some participants' views on the position of the non-abusing parent, views that will have influenced their perceptions in childhood of the safety of their immediate family environment.

a. Narratives of collective identities

Participants spoke of a number of collective identities that they now own, partially or more comprehensively, and that have provided a degree of self-validation and empowerment. Of particular significance was their identity as a survivor of childhood sexual abuse raising, for some, the complexities involved in occupying this identity. Other social identities that were felt important, included their identity as a disabled person and their sexual identity; with these latter two issues being intrinsically linked by society's denial of disabled people's sexuality. I will now endeavour to consider each of these collective identities in turn.

i) Survivor identity: "coming through your own holocaust"

The road to arriving at a place where survivor identity could be assumed, partially or more fully, was a difficult process for all participants and was complicated further, for some, by disability. Numerous factors have been influential in helping them to reach a position where they have been able to "speak out" about their experience, move forward in their lives and resist the ongoing destructive potential of sexual abuse. These factors have included, for instance, the input of family, the relevance of personal qualities and the contribution of allied professionals. I will begin, however, by looking at the concept of "survivor status" and explore several participants' views about the acquirement of this personal and social identity. Below Thomas talks about his survivor identity in positive terms and his realisation that he had, in fact, come through a process of survival, a perspective that was probably implicit in all participant's narratives, yet rarely voiced:

"I'm the survivor. And that word.... when my probation officer first used it, I laughed. I said, 'What do you mean I'm a survivor, I thought you only became a survivor if you went through Dakar, Belsen or Auschwitz, what's this survivor thing?' But she said, 'You are, you have come through your own holocaust, you've made it, you're a living witness to that and you've done that.' And I thought 'Christ yeah.' "

Thomas

In these next quotes, Lyn describes her ambivalence about the survivor identity, since it signifies, for her, the acquisition of yet another stigmatised identity and creates unease about the fact that, in reality, there is a relationship between the two issues of sexual abuse and disability:

“You struggle so hard to be seen as a person and not just as a disability that you don’t then want to add something that you also can be labelled with and no longer be seen as being you. You know an abuse case. It’s quite subtle that, and I can feel that sort of drive in me. I just don’t want to have another handy label stuck on, because that particular handy label, disability, has been there all the time and it takes such an effort to get people to see past the label.”

Lyn

“That all feeds into not being able to talk about this kind of stuff (sexual abuse) because you are there as a victim again, as damaged goods again, just when you’ve done all that work to say well there may be a disability there, may be an impairment, but it doesn’t get in the way of me being productive and happy and all the rest of it. And to talk about sexual abuse and to suggest in any way that the two of them might in some way be connected, it feels like cutting the ground away from under your feet, even though I know that it’s true, even if I know that there is stuff to be explored there.”

Lyn

Below Jean relays her concerns about a survivor identity, feeling that it precludes and potentially overrides other important aspects of the individual’s self:

“Having said that, I also feel very much that I don’t want this identity that is about being a survivor, I am much **more** than that, a lot of other things have happened in my life.”

Jean

The actual healing process, which has enabled individuals to attain varying degrees of distance from the original experience, still presents an ongoing challenge for all participants who, inevitably, have to deal with the residual emotion generated within the context of their daily lives. Below participants elaborate further on this point and, by using an analogy, Josh describes his attempts to manage his distress:

"Now I see abuse like a piece of luggage really, so what I do as much as possible is leave it at the station. Occasionally I'm back round on the train and I pick it up for a short while, but I make sure I drop it off again pretty quickly because I'm not having that bastard still ruin my life."

Josh

May's method of managing involves the creation of a degree of detachment from the experience. May also illustrates the point that, despite any amount of therapy, sexual abuse can continue to be an emotionally isolating experience:

"People may feel I must have it together to write this, don't be fooled. I can write this because I've had all kinds of therapy and I've gone over and over it, had the whys and wherefores explained. And I can detach myself, so it is like writing about someone else, even though I know it is me. The bottom line is, you can have all the support in the world, but you are the only one in your head, so no one can cope for you, and that is the problem."

May

Both Thomas and Jean comment on anger management strategies, which in Thomas's case has involved an acknowledgement of its presence and for Jean has involved a constructive re-channelling of this anger:

"Or some days I'll get up and I'll be angry, I'll have had enough and I'll be in a mood and she'll say, 'Ooo... who's in a mood then.' And I'll go outside and the kids will be saying, 'What's up with dad?' At one time I would have said 'there's nothing wrong with me,' and believe it, but now I know there is."

Thomas

"I am trying to work with my anger about what was done to me, and how to use that constructively to channel it into positive things. I am determined to 'get over it,' and be free even though I know that in a sense it's always with you, the echoes of it are there, but I refuse to let it limit my life."

Jean

Lizzie describes the emotional consequences of her abuse experience, which can sometimes express itself in the form of self-harm:

"I guess the most persistent impact, I think, has been that I am hideously self critical, and there are two key things that trigger it the worst. They are getting lost and losing things and it doesn't take a rocket scientist to work it out, does it? Depending on how tired I am, or how much pain I'm in, I'll either abuse myself verbally, or at worst slap my own face or pull my hair really hard. This is something I haven't yet been able to overcome, and it bothers me."

Lizzie

When investigating participant's actual recovery process and the means of identifying as a survivor, there have been things that have been clearly assistive in the process, and others that have impeded recovery. Here I offer a selection of quotes illustrating these important contributions. In Thomas's case, he credits the influence of a supportive partner who provided a safe base from which disclosure could be achieved. In Lyn's case, she talks about the security provided by a supportive network of friends:

"I know now, thanks to the support I've had, that it's not my fault and that there was nothing I could do. Today I am not a victim of abuse; today I am a survivor. Since my breakdown in 1995 when I told Sharon my story she has done nothing but support me, she understood and above all showed me something I had been missing all my life: love. Slowly I have come to terms with my past....."

Thomas

"It sounds so banal but talking about it and having some friends to whom I could say, gradually over time, that this happened. Some of them, who have known me since university, have said that they knew something was wrong, but they were never going to push me to say anything before I was ready and that's nice. It's confirming because it means they sort of trusted my pace....."

Lyn

Jean refers to her resilient nature, which was demonstrated in her ability to survive the experience of sexual abuse. Additionally, she makes the link between resilience and her supportive parents, an issue, which I will come back to later on in this section:

"My general resilience I attribute to my experiences, but I also have a bit of a resilient nature, I know I am a very strong person and I think that's probably a mixture of my natural inclination and my hard life. In

addition I had good loving relationships with my mum, step-dad and other adults, and I know this also helps children deal with abuse.”

Jean

Lyn and Jean talk about the influence of therapy. This included therapy occurring in a formalised therapeutic setting, as in Lyn’s case, and the personal therapeutic process happening outside formal therapy, as in Jean’s situation:

“I’m a huge fan of therapy now, I’m probably too much, and I know that it doesn’t work for everybody but it did seem to help. I could not imagine feeling like this three years ago. I couldn’t imagine living another year, but certainly not feeling as positive as I do about things, and being able to talk about it like this. It doesn’t mean that I don’t still get very shaky about it.”

Lyn

“That is where I’ve been able to make progress: really working on my relationship with my self and really building on self-love as the key thing and a way of fighting back. The very fact that I do have successful intimate relationships is a huge victory because that’s what they were stealing - the capacity for joy and self-love, to have an authentic emotional connection to myself and others, and being able to live my life and achieve my goals, this is the sweetest revenge!”

Jean

Josh and Chloe refer to the positive consequences of being able to channel their negative experience in a productive manner, in the outside world:

“So that’s why I got involved with the charity because I want to help other people. And I particularly want to help blokes, because there’s plenty of help for women, there’s Rape Crisis and all the others to help them work through it. But for the rest of us that find it more difficult to talk about those bloke things, you need somewhere safe to be able to talk about it.”

Josh

“The (disability) movement has given me the chance to take out the energy that before was just internalised, or put out into the world to attract abuse. I have found ways that I can use it as positive energy. So I can take anger and make that into something positive. It has helped me deal with the abuse and I’m not going to let them fuckers

beat me because I know what's right and wrong now, and I will fucking fight back."

Chloe

Lastly, Chloe speaks about the influence of education. Her education, she believes, has enabled her to obtain a wider, less personal, perspective on the sexual abuse experience:

"And it's a terrible thing to say that if you are not as educated or free thinking as the next person then you might have worse consequences and less opportunity to deal with it. Well that just makes me sad. I don't know if it's true or not. I mean the thing is every person will just find whatever they have got, so you just draw on whatever you have and it is always one of the things that I have had. It's not always been a good thing but it's been a useful thing at times."

Chloe

In terms of prohibitive factors, and following on from Jean's earlier quote, the support of parents, particularly the primary care giver, plays a significant part in the healing process. Here Thomas talks about his disclosure to his mother, which occurred in the context of an argument, and was met with disbelief and a general attitude of denial:

"Also I'd got into some trouble with the police through one thing and another and my sister knew about it. And I said to her, 'Look don't go telling my mother, keep it to your self, it's only a minor thing, it's not major, just keep it to yourself.' But of course she went and told my mother and my mother came to the house this particular day and said, 'Our Carol's told me that you've been in trouble with the police and that is just disgusting, you a thief, we've never had a thief in the family before.' And I just snapped; I lost it totally. And I just said, 'You have had a thief in the family before and he took four more than I've ever taken and it's called childhood,' and she said, 'I don't know what you mean.' And I said, 'You do know what I mean, you do, you know that my stepfather was abusing me, was abusing Carol, was abusing John and was abusing David too, you know it.' She tried to say that she knew nothing about it and we basically ended up having a real shouting match. I was swearing and cursing at her and eventually told her to get out of my house."

Thomas

"There are times when she'll come over and she will say...let's give you an example, I've bought a green house recently and she said, 'Oh that greenhouse is far too big, what the hell are you doing with a big green house like that?' And I just feel like turning round and saying, 'so I can go in it and escape from shit like you.' But Sharon will say, 'Well, he wants to grow lots of different things, don't you Thomas.' And when she goes, Sharon will tell you, I just go in the study and I sit there and I'll roll fag after fag after fag. As far as what happened to us kids, see that rug there, she sweeps it right underneath. Good, great and brilliant: Jack Brown, good, great and brilliant. She always talks of his positives: 'it would have been our wedding anniversary today, he always bought me roses on my wedding anniversary.' "

Thomas

Denial is the theme that predominates this next quote of May's. May's mother's concern for children sexually abused within the context of the extended family is not connected up in any way to May's sexual abuse, which her mother was aware of at the time. Her mother's attitude compounds and heightens May's sense of worthlessness:

"I am not sure what I find most difficult: the fact that my mother knew and did nothing, or that she has somehow managed to blank out what happened. I say this because she is very critical of the person that knew in the case of abuse in the extended family, saying they should have done something to protect the children. She also talks about it at every opportunity, saying how upset and devastated my stepfather would be if he knew, which just reinforces my feeling that she does blame me, and feels it was my fault. All of this makes me feel that she was quite happy to let anything happen to me because of what happened before she met my stepfather, as long as she kept the money she had and didn't end up on her own again. Counsellors, and other support I have, suggested to me that perhaps she raises the issue all the time because she feels guilty and wants to bring it out into the open, so she can apologise. I do not agree, I think she is scared that I might say something to someone and she will be in trouble, as this is what happened with my extended family. I think my mother thought that nothing would happen to her because she didn't take part, and also my stepfather is no longer around so in a sense it is over and done with."

May

Lyn's inability to confront and disclose her abuse is hampered by the deaths of both of her parent's, leaving, for her, a degree of unfinished business:

"I wish they were alive. They are both dead now and that makes it difficult because now I would like to talk to them about it. I would like to be able to say to my dad, 'just what the hell do you think you were doing? What was it? What was going on?' I feel a mixture of things towards him, its not just anger. With my mother I'd like to say, 'how much did you know?' To be able to say, 'look I can understand if it was a big problem for you, I just want to know if you noticed at all?' "

Lyn

Feminist author, Naples (2003), defines a survivor as "a person who has self-consciously redefined their relationship to the experience from one of victim" and I start by deconstructing this commonly cited and definitive duality of victim-survivor. I argue that these concepts need to be given a further degree of consideration, since they have the potential to become oppressive and limiting categorisations, with the full survivor status never truly being achievable. In actuality, as can be seen from participant's quotes, although essentially survivors of this experience, the status of "victim" and "survivor" are not, in reality, static concepts. Participants in this study have tended to oscillate between these two restrictive categories, influenced by factors associated with their environment. The defining term appears to rest in a subjective measure of the degree of emotional distance, which has been achieved from the experience, and how much sexual abuse is perceived to adversely affect the individual's life at that particular moment in time. This finding reflects, I believe, the limited and limiting number of identities currently prevalent in the child abuse literature.

The act of "speaking out" and "breaking the silence" is seen to be central to the therapeutic alliance, which aims to initiate the healing process for the individual (Reavey and Gough, 2000). It has also been instrumental in the wider societal consciousness raising process, founded in the activities of the Women's Liberation Movement of the early 1970s, which refocused its concerns from domestic violence to child sexual abuse. Naples (2003) contends that the emergence of a depersonalising survivor discourse within contemporary society politicised the problem by moving it, more squarely, into the public domain. It also illustrated the diversity of personal experience by highlighting such issues as race and gender and, in doing so, created a sense

of personal empowerment for the individuals concerned. Some of these political factors have also been influential in motivating participants in this study to become involved in the research process (Chapter Five, page 184-185). The politicisation of the issue, and the questioning of the sanctity of the family, also generated a societal “backlash” with the formation of such groups as the False Memory Syndrome Foundation in 1992 (see page 14). This development created, at that time, a generalised suspicion of therapists and social workers and attempted to re-position a very real social phenomenon as isolated individual incidents (Scott, 2001). Additionally, it undermined much of the political work that had gone before. This issue of recovered memory and false memory will be debated further in Chapter Five.

As illustrated by participant’s quotes, Naples (2003) acknowledges the multiple methods that individuals utilise to reinterpret their childhood experience. She also raises the issue that individuals have differential avenues available to them to “speak out” complicated and compromised even further by the experience of race, gender, impairment etc. The earlier quotes of Lyn, in particular, illustrate the difficulties associated with “speaking out” for individuals who are members of other stigmatised and objectified minorities. Whilst some authors advocate the possibility of positively integrating multiple identities into the sense of self so creating an increase in self-esteem and pride (Reynolds and Pope, 1991), Vernon (1999) illustrates the dilemmas this poses. As a result of investigating the issue of race and gender within the disabled people’s movement, she rejects the notion of parity implied in the concept of simultaneous oppression discussed in the writings of such authors as Stuart (1992). She argues that this theory is neglectful of the “complex interactions between different forms of oppression” and concludes that the experience of one stigmatised identity, in this case survivor of sexual abuse, is often exacerbated by the presence of another marginalized identity. The risk incurred in speaking out, in this instance, includes the possibility of further displacement and alienation.

The problematisation of the survivor identity also marks significant progress made within the healing process. Here the shift from victim to survivor status,

as can be seen in Jean's quote, eventually results in this new identity being seen as too constricting, since it denies other important aspects of the self (Phillips and Daniluk, 2004). Phillips and Daniluk (2004), in their research, evaluated the self-perceptions and identity re-construction of seven female incest survivors after a period of therapy. They found that in the initial stages of the recovery process the survivor identity was integral to their ongoing ability to cope. As the process progressed, however, it became important to relinquish this identity in order to move forward, whilst at the same time "drawing from its richness."

Within my study all but one participant had undertaken counselling or therapy, which mostly had been perceived to be helpful. Some of the changes in self-perception, discussed by Phillips and Daniluk (2004), also applied to the healing process experienced by my participants. Some of these changes were not seen to be solely attributable to formal therapy. They were, in some instances, positive expressions of power utilised in other areas of the participant's life such as employment and/or education (James et al., 1993).

Of particular relevance, in the issues identified in the work of Phillips and Daniluk (2004), were the feelings of being more visible in the world with their internal feelings being more solidly connected with their external presentation. They also identified a sense of loss regarding the time spent surviving and recovering from sexual abuse, plus the opportunities missed in terms of relationships. These issues undoubtedly had some relevance for participants in this study, particularly May (see page 138). Phillips and Daniluk's participants spoke of other aspects of the self, particularly resilience, which had developed in childhood as a form of self-protection and which allowed them to keep functioning, an issue also raised by Jean and highlighted in the work of Zimrin (1986). Finally, they identified a personal growth related to the process of coming through the healing process. For some participants in this study, the major losses identified were the "loss of childhood" and "loss of self." These are issues, however, which will be picked up again in Chapter Five when the concept of loss will be examined in relation to narrative reconstruction.

Contrary to the findings of Phillips and Daniluk (2004) where women felt they had moved to a place where their sexually abusive experience was part of their past and the therapeutic work was, in effect, completed, this research indicates the opposite. The views of participants in this study tend to be that despite therapeutic work, or other types of input, the process of healing is an ongoing one, which supports the writings of such authors as Warner (2001). Warner argues that individuals have “differing levels of engagement with their abuse, at different times and in different situations.” So, in addition to the influence of pressures presented by their immediate environment, the stage that the individual is at in their life may mean that active engagement with the sexual abuse takes less priority, even if it contains some relational substance.

The work of Zimrin (1986) also raises another important issue with regard to the healing process. In addition to cognitive ability, the children in her large scale, long-term study that fared the best in early adulthood were individuals that had a significant adult in their life. This was an individual, such as a teacher, who they trusted and who instilled in them a degree of confidence and encouraged them to succeed (see Lyn and Thomas experiences, Chapter Three, pages 71-72). The significance of this positive adult figure also raises, for me, the position of the non-abusive parent. The participants perception of their mother’s emotional availability will be considered in more detail later on in this chapter, but here I briefly consider the subject of adult disclosure and the response of the non-abusive parent.

The barriers to disclosure for children are well documented in the academic literature (Goodman-Brown et al., 2003) and have already been touched upon in Chapter Three, page 109. This difficulty in disclosing when young creates a situation whereby the majority of survivors of sexual abuse only feel able to “speak out” later in life, often in the context of a safe long-term adult relationship (McNulty and Wardle, 1994), as described earlier by Thomas. Baker (2002), by drawing from a sample of women who had received therapy in relation to their sexual abuse, contends that no one antecedent generally precipitates disclosure from adult survivors. The factors range from concern

about other children's welfare that are still in contact with the perpetrator, to the accumulation of psychological distress over a period of some years.

McNulty and Wardle (1994) argue that the reaction of others in a person's social support network to that disclosure plays a significant role in the well-being of the individual, with the reaction of family members, particularly the mother, "posing a serious life stress which can increase the incidence of illness." In fact, Barker (2002) feels that validation and support by the mother can be more significant than the abuse itself. McNulty and Wardle (1994), by drawing on the work of others, contend that for those who experience positive responses following disclosure, as was the case for several participants in this study, they experience fewer psychological symptoms and higher self-esteem. For those that meet with hostile and rejecting attitudes, such as Thomas, the impact can be profound. Equally, I would conclude, for those who are unable to confront their mothers because of death, as in Lyn's case, or because they assume a negative response, as in May's case, the impact on self can also be detrimental.

ii) Disability identity: "understanding the politics of oppression"

Participants also spoke about their disability identity, which, for some, was initially subsumed by the experience of sexual abuse but later emerged, to be given differing degrees of meaning and significance. Several participants expressed a strong disability identity, which found expression in their personal politics and their involvement in the disabled people's movement:

"When you start to understand the politics of oppression and what it's about, that is so empowering and it gives you a power but also it gives you knowledge and advantage. It gives you a framework that applies to all different stuff in life including sexual abuse. And I think that's a gift."

Chloe

"I'm actually in a place where I can work on something I really care about, that's personal to me, that I want to make an effort along with everybody else to change and I've got a whole menu of ways I can do it. You're in a place where when it works right, and it isn't always like

that, but when things are being well practiced by good people, then it's good. It's about finding what skills everybody has got, and all disabled people have got something, we've all got different skills and there are so many different jobs to do. So it means that I've had chances to use all my different skills that I didn't use before."

Chloe

"The first one I joined was the women's movement before there was the disabled people's movement, and even before then I was campaigning in my own little ways for children's rights, for them to be treated with respect, disabled children in particular. So I would volunteer to speak at conferences and put forward, what was really a remarkably political case in those days."

Lizzie

Jean talks about disability identity by raising, as she did in the last section, the issue of multiple identities and the fact that, in relation to multiple stigmatised identities, this can offer its own advantages:

"In terms of the lesbian and gay community I've always felt on the margin because of disability. As a teenager I knew that there's no way I was ever going to make the 'A' group. I was always 'spaz,' I was always this gender bending tomboy freak, and so in a sense I was able to really build an identity for myself that was outside a lot of those 'normal' things."

Jean

Lyn's quote raises the issue of internalised oppression, which can create difficulties for some disabled people in expressing their needs and openly identifying as a disabled person:

"It becomes ingrained and certainly my mother's training had been, and what she handed on to me was, it must not show, you must not do anything which draws attention to yourself. For her, when she went out, she would always put something over her arm to cover up the fact that it wasn't there. She would use a cardigan or her handbag, she had a little stump that ended here and she would always drape something around it. She would never allow herself to be photographed with the stump showing. The thing to do is to try and hide it, even if people know about it; you are succeeding if you appear not to be any different. She used to make me feel really guilty, and I'm sure she didn't do it deliberately, but she would say it was much easier for me to do that because mine didn't show. Hers showed all

the time and deafness didn't show, so I had that advantage. So anything you do that is negative and makes you stand out is wrong. It's okay to stand out if it's for something good like being good at school or whatever, that was okay, but creating problems, drawing attention to yourself!"

Lyn

"Now days I'm much more assertive. I think that the accommodations that have to be made for people with disabilities should be made, and the only reason that they seem such a pain is because people aren't used to making them. When it comes to making allowances to enable me to hear and participate at work then I'm pretty stropky and mostly I get what I need, and I'm not particularly retiring about that. When I'm feeling tired, or in a strange place I may be more cautious. But it's still an effort to an extent, there's still, in the background, this thing that you have no right to be asking for this, this extra effort to be made, you've got to justify it in some way. And one of the ways that I've justified it is by working hard and being productive and being a good person, being unproblematic and being a productive member of society."

Lyn

For Josh, disability appeared less central to his identity and whilst acknowledging others discriminatory attitudes he overrides these by playing down the issue of difference and questioning notions of bodily perfection:

"I mean for very many years I tried to do something about it, now I've stopped trying to do something about it, and it's me and I use it. So now in my later life I give presentations and they get the stutter as well because it's part of me, and it makes it more exciting as far as I'm concerned, so I don't let it get in the way. And I've never let my disability get in the way; other people have let my disability get in the way of me getting on. I've never allowed it to happen, I mean if I can't do something because of my disability that's fine, not everybody is good at everything, so it's other people who have held me back, and I've took no notice anyway, and I've got on in my own sweet way, and it's the only way to do it."

Josh

In terms of being able to construct a disability identity, Shakespeare (1996b) cites a number of factors, which are prohibitive forces in the facilitation of this process. These factors have included, amongst other things, the generalised

devaluation of disabled people within society (as detailed in Chapter One), which can be seen to have an adverse effect on disabled people's perception of themselves, affecting their willingness to be identified as a disabled person. This issue can be best observed in Lyn's comments relating to her own and her mother's struggles to be perceived as a non-disabled person. It also includes the fact that (as described in Chapter Three, pages 102-104) some disabled children still grow up in families where they are considered a "problem" or "burden" and when they do eventually go out into society, they may be isolated from the means to build a positive personal and collective disability identity. In addition, Swain and Cameron (1999) posit the influence of impairment-specific categorisations within society, which produce a comparative discourse of "more or less disabled" and which, then, erode the potentiality of the collective.

The emergence of the disabled peoples movement (as described in Chapter Two, page 23) marked the beginning of a process whereby societal norms began to be challenged, disabled people's oppression was named and exposed (Campbell and Oliver, 1996) and disabled people started to be seen as a collective force. The uniting principle embodied within the evolution of the disabled people's movement, and as present in Chloe's quotes, has been recognition of the socially oppressive forces that exclude disabled people within society and a focus on change and empowerment (Watson, 2002). The later extension of the social model brought about the "affirmation model of disability." This model describes the appearance of positive personal and collective disability identities, particularly as observed within disability arts. These identities are characterised by disability pride, the problematisation of the concept of normality (an issue raised by Josh), positive ownership of the impaired body, and a positive re-evaluation of the life-style of disabled people (Swain and French, 2000).

Additionally, within this culture, there has emerged a reclaiming of language, with the use of the word "crip," for example, originally used by the non-disabled world with derogatory connotations, now being used as a symbol of solidarity within the disabled community (French Gilson and Depoy, 2000). In

fact some authors, by building on the work of Swain and French (2000), feel that the total relinquishing of the dichotomous normal-other divide may also provide insights for other marginalized minorities operating outside of the disability sphere (Galvin, 2003). The actual individual process of “coming out” and claiming a disability identity marks, according to Swain and Cameron (1999), a declaration of belonging to a devalued group in society. It can take, for some, a number of years, and is complicated further by the issue of internalised oppression, an issue which will be discussed next. Clearly, Chloe’s quote illustrates the acquisition of a strong individual and collective disability identity, with the recognition and confrontation of societal oppression being prevalent in the quotes of both Chloe and Lizzie.

As already described in Chapter Two (page 23-24), criticism of the essentialism embodied in the early writings of disability structuralists, who viewed disability identity in fixed terms, raised concerns for a number of disabled feminists. As already discussed, these concerns centred round the neglect of other aspects of disability identity (Crow, 1996). This call for an extension of analysis later led to consideration of the psychological and emotional effect of disability on the individual’s identity formation (Thomas, 1999). Working along similar lines, Swain and Cameron (1999) detail the processes of self-punishment, denial and passing (as normal) as being some of the main personal strategies used by disabled people to deny their physical and emotional reality.

Reeve (2002) maintains that this internalised oppression is variously experienced, and I would argue, as could be seen in Josh and Lyn’s quotes, often takes a substantial period of time to disentangle and truly understand its effects. By drawing on the work of Shakespeare (1993), Reeve also asserts that by raising the profile of impairment within the disabled people’s movement, and gaining a greater understanding of these issues, more disabled people may feel able to claim a positive disability identity.

Both Reeve (2002) and Benjamin Darling (2003) refer to the fluidity of disability identity, with Benjamin Darling (2003) arguing that whilst academics

continue to produce work with differing ideological positioning, very little is known, in reality, about this particular population's identity formation. By intensive literature reviewing using a number of different sources, both academic and autobiographical, Benjamin Darling proposes a typology of disability identities. This typology recognises the two main oppositional constructs, which involve, firstly, the adherence to the cultural majority norms relating to appearance and achievement and secondly, as typified by Josh's quote, the minority view which questions norms and accepts diversity. This typology, however, also identifies a number of derivatives of these two positions. Benjamin Darling proposes that an individual's disability identity is dependant upon a whole range of structural and opportunistic possibilities rather than any psychological determinant, and that individuals positioning is liable to change over time with an accompanying commitment to that one particular position.

Of particular relevance to this research, Benjamin Darling (2002) cites the categories of "normalisation" and "situational identification," which raise, for me, the wider issue of multiple identities. Benjamin Darling's normalisation category includes individuals who accept the norms of wider society and manage to achieve a lifestyle similar to their non-disabled peers, by sometimes trying to pass as "normal." Watson (2002) offers a different perspective on this categorisation, finding, in his study, that whilst many individuals did not build an identity based on impairment, at the same time they did not accept the societal notion of the "normal body," a theme referred to in Josh's quote. They rejected physicality as a determinant of the self, which Watson proposed was symptomatic of their attempts to play down their impairment, in order to expose other aspects of their identity. Similarly, Benjamin Darling's category of situational identification, described individuals in this category as being shape shifters who adopt whatever identity seems appropriate at the time. These individuals are unwilling to choose between competing positions, so making activists suspicious of their intentions. I believe that this categorisation could also be understood in terms of multiple identities, with different identities sitting along side each other.

Shakespeare (1996b) argues that the recognition of multiple identities, both within the disabled people's movement and within Disability Studies, offers no significant threat to the disabled people's movement. Whilst acknowledging the situational determinants of identity and the power of one identity to transcend others, he calls for openness to variations in disabled people's narratives, which reflect the diversity of their lives. A recognition of multiple identities also requires, in his view, an appreciation of the tensions that may arise between these political identities, particularly if they are stigmatised identities (Vernon, 1999; Appleby, 1994) and also the freeing potential that this can also bring about. Authors such as Peters (2000) believe that actual participation in the disability culture should be a matter of individual choice, and that solidarity can still be observed, whilst not being enmeshed in the disability culture. The fact that all the participants for this study came through disability publications and websites, illustrates their involvement, in some way or another, with the disability community.

iii) Sexual identity: "trying it out with a disabled person"

Within this section the question of disability and sexuality will be examined, with consideration of how this has become complicated by the experience of child sexual abuse. The following quotes illustrate the intersection of sexuality, gender and impairment, and here Josh talks about how his self-consciousness, relating to his impairment, was not reflected in his ability to attract female dating partners:

"My disability didn't seem to be too much of an impediment to my ability to attract members of the opposite sex. I think that when I was younger I felt that people always noticed that I had a disability and that I looked different, or I couldn't move my arm, and that didn't help with the relationships because you just assume that they wouldn't be interested in you because you had a bad hand or you had a limp. But that actually wasn't the case because when I did have girlfriends it didn't matter. It mattered to me, but it didn't matter to them, it wasn't an issue. In the same way that it's not an issue with my wife. So it's an issue that I've had in the past, but now days I'm not bothered because I'm in quite a secure relationship, it's a long term relationship, where I'm loved for all of me."

Josh

The reality for women, however, can be somewhat different. Lizzie and May talk about their experiences of adolescence, which included an exclusion by other teenagers from the sexual scene, in Lizzie's case, and the neglect of a developing sexual identity, in May's situation:

"With regard to discovering my sexual identity in adolescence, the overwhelming thing was not feeling part of that. I only had one friend that discussed boyfriends with me. My friends excluded me from the realms of sexuality, you know desexualising me, or asexualising me. Certainly when I got my first boyfriend who was a hunk, there was an absolutely overt comment from another girl, 'How on earth did **you** manage to land him?' I didn't see myself as a sexual being."

Lizzie

"I Know my mum ignored my developing sexuality, I realise that because I had to watch my sibling going through it. They got the chats about periods, the training bra, the support and encouragement to do things, to go places, while my development was ignored. I think I got my first bra at 15 (and even this wasn't new), I was very large and I should have had one much sooner. I also mostly had second hand clothes. I think me being a teenager was ignored in the hope that things would stay the same in the family."

May

These assumptions regarding an asexual identity can create limited dating opportunities for disabled women, as Lizzie describes, and can affect their own self-perceptions. Lizzie's second quote illustrates the fact that this process of asexualisation can also affect other aspects of their life, including pregnancy and childbirth:

"And I really think that I am still vulnerable, not in the sense of.....I am married to someone who I love deeply, so not in the sense of needing to rush out and do anything about it, but if anybody comes on to me well the first reaction is always, 'I don't believe it' and then when I've made myself believe it, it's 'wow.' But looking back at it most men who.....I think that most of my relationships were with men who were already in some other relationship and they didn't mind trying it out. And then, when I wanted to take it more seriously they backed off immediately; that was most of my relationships. And I think that probably the number of times when the push came from the bloke rather than just me is quite small."

Lizzie

"I was in hospital for three weeks with the girls and some of it was awful really because they were so totally unprepared, you know. And I had midwives saying, 'I can't remember having a disabled mother in here before.' And they didn't even have a bath board to help you get into the bath; I had to bring that all myself."

Lizzie

Additionally, Lizzie raises the issue of violence and the real dangers that disabled women face:

"In fact I came very close to being abused by one of my colleagues during that time, sexually. And I had to summon all my strength. This was a man who worked in a sensory team and he came to visit me. I could get up and answer the door but that was all. I was just lying on my back the whole time and he managed to touch my arm in such a way that he brushed my breasts, and that was it. I wrote to him and I absolutely don't remember what I said now but it was something to the effect of 'I never want to see you again in my house and please don't come and visit me again.' I'm convinced that if I hadn't been strong enough by that point.... well that was only by way of being a stropky git really."

Lizzie

In this next selection of quotes, May, Lizzie, Lyn, Josh, Thomas and Chloe speak about the additional complicating consequences of child sexual abuse. For May, she talks about her concerns in adolescence where she was preoccupied with the possibility of becoming pregnant. Equally, Josh and Thomas talk about the problems created by a homosexual learning experience on a developing heterosexual identity:

".....my teenage years were spent feeling 'why can't I do what other people do,' and worrying about getting pregnant. I always made sure people thought I had a serious boyfriend, just in case. This usually backfired as people found out, but the alternative was much worse."

May

"My problem was that my life was so dominated by the abuse, and it was male on male abuse, so that brought into focus my sexuality. I did wonder about my sexuality because it's confusing at that age anyway, and you see my learning experience had been homosexual

learning experience, but I never went down that road, I ended up in heterosexual relationships.”

Josh

Thomas, in particular, believes his stepfather’s comments were located in his own sexual confusion and homophobic belief system:

“Female wise, I didn’t start developing relationships until I was like fourteen or fifteen and that was only through my old man constantly saying ‘you’re gay, you’re queer, you enjoy being abused,’ which he did a lot of. I think I’d got something to prove to myself and that’s why I lost my virginity at fourteen, I set out to prove that I wasn’t gay, and I did.”

Thomas

Lyn talks about the effects of child sexual abuse, in early adulthood, on her ability to assess appropriate/inappropriate sexual behaviours in others, and identify potentially dangerous situations:

“A year after my mother died I was raped and I’m sure now that that happened, without in any sense letting the two people that did it off the hook, I’m sure it happened because in part I didn’t know, I didn’t understand about signals and boundaries and managing that. The two men involved were two friends of mine and it was in a situation in which I should have been able to tell that there was something not right there. I can remember feeling uneasy about the situation. They were both drunk and it was post a party, post an afternoon party. I was sober and they, I think, agreed it before hand. They were not close friends, but there was a group of us in a way that you have at university sometimes. I would say I saw one or both of them several times a week, socially. I’d been out with one of them once but it hadn’t really taken off and it was possible that this one felt jealous. But there were alarms bells ringing and I ignored them because of my life experiences. It may be too easy to blame it on that, but I didn’t know how to read men in the same way that I think a lot of young women do know how to read them.”

Lyn

Josh speaks about the difficulties he had with trust in his early sexual encounters, and how this impacted on the relationship:

“One of the biggest problems that I had was trusting somebody, and if you can’t trust somebody... I had this big secret and was worried they were going to find out and that was extremely difficult. I had a few girlfriends, but no sex, and that was very difficult, I tended to go for one or two nightstands. And it wasn’t until I got to about twenty that I actually had sex with a woman and the interesting thing was.... I was at a party and I’d had a few drinks and we were walking home across the common, and we ended up on the grass and then we had sex, but the interesting thing I noticed there, and this happened probably a couple of times afterwards when I was with other women, whilst I got the erection, had the sex, I never actually came, and that was a holding back thing.”

Josh

May also talks about her general lack of trust in members of the opposite sex, and later discusses the problems that occur in relation to disclosure:

“Relationships are a nightmare because I find it difficult to meet people, and when I do, instead of enjoying their company, I sit there terrified that I am going to do something that will give off the wrong signals and make something happen to me. I am so conscious of this that friends tell me I give men the brush off without even knowing it. I don’t like having people in my house because I don’t feel safe. If I have to have work done then I make sure that someone is with me, but even then I can feel myself getting jumpy. If anyone is persistent enough to want to start a relationship then I agonise over when to tell them about my past. Usually this then is met by one of two reactions: the first is that they look at me like dirt and I never see them again, the second is that they say they understand. In some ways this is worse because it means people having to deal with very difficult issues.”

May

Looking at participants’ more recent sexual relationships, it can be seen from the following quotes that, for May, whilst disability may have created an increased risk of her encountering aggressive and violent men, her situation is made more difficult by the sexual abuse experience, and her family’s attitude towards impairment as she was growing up. May’s last quote illustrates how the sexual abuse has, additionally, affected her ability to objectively assess potentially abusive relationships, prioritise her own needs and, notwithstanding economic factors, find the impetus to leave the abusive situation:

"I think one of the biggest consequences of my abuse was being involved in a subsequent violent relationship. It started like most do with the person being really kind and caring, and I could not believe that someone actually wanted to be with me, for me. Because of some of the difficulties, which I will explain later, I had to tell them about the abuse, and then they started to criticise me, only small things at first, but then more and more. Because I'd experienced the same criticism whilst growing up I just thought 'yes, it is me.' Each time I was hit or raped I was told it was my fault, and because I had grown up being told this I just thought 'yes, it is.' "

May

"My early relationships made it hard for me to separate out what was a consequence of child abuse and what was from this relationship. However I do feel that my parents set me up for this relationship because of the things that happened and the way I was treated whilst I was growing up."

May

"The second relationship I am still in, although it doesn't make me happy. I feel I am back in my childhood where their needs come before, or are at the expense of, mine. And although they say they love me and I am important, I don't feel it because of the things they do. I think we will probably split up before the end of the summer, despite their assurance that things will be different and they will be different. The situation has gone on for the last 3 years and I feel it is just a replay of my childhood and my violent relationship."

May

May and Chloe also talk about the their current difficulties in enjoying intimate sexual encounters. May refers to the consequences of "break through memories" or "flashbacks" and Chloe's speaks about her perceived promiscuity and her tendency to dissociate when involved in a sexual encounter with a man:

"One of the most difficult issues is the physical side of a relationship: touching, hugging and kissing. I find it difficult because it can either cause flash backs, or I start to feel trapped. The sexual side of a relationship is even worse because this is where men feel you are taking it out on them if things go wrong. By wrong I mean flash backs that mean I just have to get away. I usually end up in the shower, or I end up sleeping somewhere else because I do not feel safe, neither of which reactions you hope for when you sleep with someone. One of the worst things for me is their inability to realise that this is

something that is always there, whether it shows itself or not. In both of the relationships that have got this far, my partner has thought 'right, we are over the difficult bit, we have shared a bed, had sex without anything happening, so everything is okay now,' then something happens. Then they feel they have done something wrong, or believe that because I can't take it out on the people that did it, I am taking it out on them."

May

"Right now, where I'm at with sex is if I could just switch it off so that my body never wanted to have anything to do with it again, I fucking would. If you could just take a celibacy pill...because my sex drive has done me such tremendous damage, what I've done as a consequence of having it. I'm starting to associate it with bad things."

Chloe

"Through having this conversation with my friend I could actually see that when I sleep with a man only a small piece of me goes to bed with him and the rest of me is somewhere else. But when I went to bed with Jean that large piece went to bed with her. So I'm at a very interesting point in my sexuality. I'm sort of looking at things and asking what does it all mean. The side of me with my brain attached that was with my girlfriend was the whole me, and when I actually try to put that piece in bed with the man it doesn't work."

Chloe

Both Lizzie and Lyn offer comparative views about their particular situations. Lizzie feels that the consequences for her sexual relationships could have been more difficult if the abuse had been intra-familial and extended over a longer period of time. In Lyn's case, she attributes the lack of problems to her choice of partner:

"The inability to enjoy a sexual relationship, as experienced by some survivors, was counterbalanced by 'thank god I've got a sexual relationship,' but if the abuse had happened over any longer a period, if it had happened in the family, things could have been very different. I just think that I have escaped with minimal damage really."

Lizzie

"Our physical relationship, our sex life, was fine and maybe if I'd been with a man it wouldn't have been fine and I would have been prompted much earlier to do something, but it was okay."

Lyn

Lastly, May talks about the physiological repercussions of being sexual abused, which has affected both her ability to become pregnant and undergo further investigation into the problem. Similarly, Jean talks about how the sexual abuse has prevented her from being able to tend to her sexual health needs:

“One of the relationships that I’ve had since getting out of the violent relationship broke down because we wanted children and it wasn’t happening. We did see a doctor, they felt the problem could be a combination of the things I have gone through, but to be sure I would need tests, which I couldn’t face. My partner said it didn’t matter, I had been through enough, but I couldn’t cope with it, I felt I was denying him the thing he wanted most.”

May

“I’ve never been able to have a smear test. My doctor has been very good and I’ve talked to her about why and we still talk about it. It’s still one of those things, which she checks in with me about: ‘where are you at with that?’ And I still don’t feel like I can do it, I really don’t. And for me it’s a tricky line that I walk, I need to keep my mental health well enough to keep my life going, I can’t afford to go over that edge again.”

Jean

In terms of setting the general scene in relation to sexuality, prior to the 1960s, and within academic discourse, there continued to exist an unquestioned duality relating to masculinity and femininity, which drew its power base from biological determinism and equated masculinity with power, strength and intellectual superiority and femininity with passivity, weakness and procreation (Bohan, 2002). These dualities still hold some currency within wider society today and have influenced the experiences and perceptions of participants in this study to variable degrees. Second wave feminism brought about the questioning of the social arrangements that centred round these dualities, with feminist writers, such as Butler (1990), deconstructing the meaning of sex and the ways in which it has been “written into our bodies and into language” (Van Lenning, 2004).

Subsequent authors such as Burkitt (1998), whilst acknowledging the contributions of postmodernist writers such as Butler, have attempted to ground the theorisation of gender identities and sexual variations, by refocusing instead on the power relations in which discourse is constructed. These power relations, he argues, operate at both a macro-level, when considering the interaction between race, class and sexual politics, for example, and at a micro-level when examining the interactions of parents and their children. Such dynamics are clearly visible in Thomas's experience where his sexuality was constructed within a working class mining community and in opposition to his stepfather's homophobic views and taunts.

Within this contextualised academic debate, little attention has been paid to the ownership and expression of sexuality in disabled people's lives, and even within Disability Studies the issues have been neglected for the furtherance of more pertinent concerns relating to oppression and exclusion. Shakespeare (2000b) and Shuttleworth (2000) summarise a number of prohibitive factors, which have acted as deterrents to disabled people enjoying sexual relationships. Some disabled people, they argue, particularly those who have grown up in segregated institutions, have had limited access to sex education and information. As can be seen in the experiences of Lizzie, for those who encountered mainstream situations, they have generally been excluded from the adolescent social scene where early sexual rehearsal begins. Sometimes, as can be seen in May's situation, parents nurture an asexual identity by giving negative messages relating to the potentiality for a sex life in adolescence and adulthood. Many disabled people, they argue, have had limited access to the work place, colleges, bars and clubs, places where they may be able to meet potential partners. Some disabled people, because of internalised oppression, may lack the self-esteem and confidence to communicate with somebody whom they feel attracted to. Additionally, the authors believe that society's ideal of attractiveness has effected some individual's perceptions of their ability to establish sexual intimacy, an issue illustrated in Josh's earlier musings on the subject of his sexuality. In this sense, and using a postmodernist analysis, an asexual identity has been written into the bodies of many disabled people.

Picking up on the issue of societal ideals, Shakespeare (1999) argues that, for disabled men, the hegemonic notions of masculinity embodied in stereotypical male heterosexuality, which rejects physical weakness and emotionality, presents a conflicting ideology, which needs to be incorporated into disabled men's sexual identity. For women, he argues, the stereotypical notions of femininity and disability reinforce each other. Perhaps one of the most commonly cited pieces of research relating to the management of the masculinity-disability conundrum is that of Gerschick and Miller (1995). These authors, by employing qualitative research methodology with ten disabled men, identified three common management strategies. The first group included men who did not overtly reject the predominant ideal, but reinterpreted it in line with their own abilities and strengths. The second group of men had internalised society's ideal, despite their inability to meet many of them, resulting in varying degrees of inner conflict. The final group resisted the prevailing ideal of masculinity and instead focussed on the potential for creating alternative masculine identities, emphasising their status as a "person." For Josh, the only male participant in this study with a visible impairment, his strategy appeared to be more consistent with a mix of approaches (outlined by group one and three). The findings of Gerschick and Miller have since been replicated in the work of both Shakespeare (1999) and Shuttleworth (2000). Shakespeare found that many of his participants employed, as I suspect Josh does, a mixture of approaches when constructing a psychosexual identity. Shakespeare believes that the experiences of disabled men have much to offer non-disabled men in terms of deconstructing and redefining notions of masculinity in less oppressive ways (1999).

For disabled women, cultural stereotypes of impairment reinforce gender stereotypes and, by doing so, bring into sharp focus their perceived inability to fulfil a number of pertinent roles considered to be inherently female (Hanna and Rogovsky, 1991), including that of parenthood. Howland and Rintala (2001) investigated the dating experiences of thirty-one disabled woman with physical impairments and reported a range of negative experiences which support the argument that disabled women are often seen in asexual and

objectified terms. All the women, in their study, were older at the time of their first date or first serious relationship, with potential dates, as described in the experiences of Lizzie, being less likely to initiate the first move by comparison to the experience of non-disabled women. Even for socially outgoing individuals with many friends, these friendships were less likely to develop into romantic encounters compared to non-disabled women. Disabled women often felt that impairment got in the way of them being seen as a person, with a number of potential dates being deterred from approaching a disabled woman because of a mistaken belief that they were unable to have sex. Sometimes the prejudice of family and friends discouraged a potential date from becoming involved with a disabled woman. Lizzie's reference to a sexual partner's fetishistic behaviour i.e. "trying it out with a disabled woman" does not appear in the work of Howland and Rintala.

The authors reported a wide degree of variation in dating habits with some disabled women being fairly indiscriminate about their choice of partner, feeling pressured to date anyone for fear of being left with no-one. The fear of rejection was a strong theme that emerged in the study with some women denying their own needs and identity to compensate for their perceived failings, and others tolerating overly controlling partners. In many cases these control issues resulted in emotional, physical and sexual abuse, including rape. A number of these issues were raised by May in this study, but their causality was seen to rest in the child sexual abuse experience. Sometimes women's lack of dating experience led to a naivety in situations that would set alarm bells ringing in non-disabled women's minds, an issue that was raised by Lyn, but also accredited to the experience of sexual abuse. A woman's perception that a partner was interested in her for the wrong reason was sometimes born out in the case of domineering and abusive men, who had assumed that because of a disabled woman's perceived vulnerability she would tolerate his unacceptable behaviour.

As can be seen in the quotes of Lizzie and May, violence or the threat of violence, particularly sexual assault, is a reality in many disabled women's lives. This fact is corroborated by research findings that indicate that disabled

women are at a significantly increased risk of violence compared to non-disabled women, with prevalence data varying from 39-85 % (Erwin, 2000). The DisAbled Women's Network in Canada illustrates that from a research sample of 245 disabled women, 40% had experienced abuse, of which 12% had been raped (Nosek and Howland, 1998). The perpetrators in this study were predominantly spouses and ex-spouses (37%), followed by strangers (28%), parents (15%), service providers (10%) and dates (7%). Based on the results of a large-scale study of 946 respondents in the US, Nosek et al. (2000) contend that in intimate relationships both non-disabled and disabled women are vulnerable to the controlling and dominating tactics of abusive men. For disabled women, however, there are additional avenues for exploitation, such as the need for help with intimate care tasks, the reduced potential for physical resistance and escape, and the absence of suitable and accessible shelters, with additional support for a woman's care needs. It seems that for those disabled women, like May, who have become involved in relationships with violent and domineering men, impairment has the potential to widen the power differential. Erwin (2000) argues that, like non-disabled women, the reasons that disabled women remain in abusive relationships are numerous and include such factors as fear of retribution, a belief that their partner will change, love and affection, and the lack of economic means for self-support. Some of these factors are present in the words of May.

Additionally, research indicates that disabled women are significantly less likely to marry than non-disabled women and disabled men (Howland and Rintala, 2001). For those women who do end up in successful relationships and decide to have children their experience, as indicated by Lizzie, can be consumed with necessity to deal with a range of other challenges. In addition to the potentially undermining attitudes of others, which are usually rooted in a perceived and feared transgression of the normative of "good / normal mothering" (Higgins, 2000), once in a maternity ward disabled women have to deal with a number of other difficult issues. Thomas (1997) asserts that disabled women, who require a degree of assistance, run the risk of receiving either unhelpful or inappropriate help or, in fact, no help at all, which was Lizzie's experience. Moreover, they are burdened with the extra responsibility

of having to demonstrate that they are good enough mothers. This point is also raised in the work of Grue and Laerum (2002) who demonstrate that disabled mothers, later on in their parenting experience, often over compensate in their mothering role in order to demonstrate an “ideal performance.”

For disabled people the experience of childhood sexual abuse adds another layer of complexity to the issue of sexuality. May's quote illustrates that, for female adolescents, the normal challenges of puberty, which in some initiate a crisis of confidence, can become amplified and distorted by both the abuse experience and the contradictory and accompanying process of asexual objectification. In May's situation, she had to contend, emotionally, with both a denial of her sexuality and, at the same time, the requirement for a strategy for dealing with the possible consequences of this very real, yet denied aspect of her self. This need for sexually abused adolescents to create cover stories, for managing any potential pregnancy, is also detailed in the work of others (Crowley, 2000).

As far as the sexual abuse of male adolescents is concerned, Durham (2003) argues that, like Thomas and Josh, the main issue that heterosexual individuals have to contend with, whilst growing up, relate to the complexity of trying to make sense of a same sex encounter. This is particularly the case if the sexual abuse has created some sexual arousal, and is made worse by a perpetrator espousing homophobia taunts, as was Thomas's experience. Some of these themes are also prevalent in the work of Gilgun and Reiser (1990). In Gill and Tutty's study (1999) of men sexually abused in childhood, the major findings included the reporting of a necessity to resolve some inner conflict generated by an early masculinity-victim identity.

Additionally, some participants in Gill and Tutty's research (1999) spoke of a number of problems related to an inability to, fully, involve them selves in a sexually intimate relationship. A precursor for developing a sexual relationship usually lies in an ability to establish some degree of emotional connectedness with a partner. All the men in their study felt that sexual abuse had created a

mistrust of others and a fear of being used and abused, an issue that is highlighted in both Josh and May's quotes. Seven of the men in Gill and Tutty's research reported having avoided sex at some period of their life or having had multiple sexual relationships. None of the men appeared to report difficulties, as Josh did, in relation to the mechanics of sexual intercourse. Most of the men, however, did at some point, find that the concept of affectionate sex was incomprehensible, with five of the men reporting dissociative experiences during sexual activity, by becoming, for instance, an observer to the event, an issue also described by Chloe when talking about her sexual encounters with men.

For some of the women participants in this study, difficulties in relation to their sexual relationships continue into adulthood, an issue which is highlighted in the work of a number of researchers (Fleming et al., 1999; Mullen et al., 1994; Fromuth, 1986). Phillips and Daniluk (2004) contend that child sexual abuse can significantly interfere with a woman's capacity to feel fully connected to their sexuality. The difficulties noted in others' research range from a fear and distrust of men, as described by May, to specific sexual problems (Mullen et al., 1994). Although not explicitly detailed in Mullen et al.'s research, I assume these problems would include experiences of dissociation and flashbacks, as described by Chloe and May. Furthermore, other authors have highlighted problems to do with sexual pre-occupation (Noll et al., 2003), an increase in homosexual experimentation and an increased self-perception of promiscuity. Promiscuity is an issue described by Chloe, but in Fromuth's study, it often fell short of a standardised rating of "deviant" sexual behaviour.

As is the experience of May, some researchers have also identified an increased tendency for women who have been sexually abused in childhood to later become involved with uncaring and over-controlling men and later experience revictimisation either in the form of domestic violence (Fleming et al., 1999) and/or rape (Fleming, 1999; Mullen et al., 1994; Fromuth, 1986). In terms of explanation, theories range from pathologising and individualising concepts, which involve the victim's "addiction to trauma" (Herman, 1992) to more sociological perspectives, which consider the individual's wider social

positioning. Mullen et al. (1994) assert that it is the child's developmental disruption, as will be described in the next section, and as embodied in May's quote (page 136), that interact with factors in the family background (such as disability in this case) so creating damage to a person's self-esteem and a limitation in the acquisition of personal agency. These factors, Mullen et al. believe, can subsequently result in an increased tolerance of the abusive behaviour of some men. In fact, authors such as Fromuth (1986) assert that family background is a better indicator of later problems than sexual abuse itself.

Lyn raises another issue, which also warrants some further consideration (page 134). A compromised ability to "read" dangerous social situations, potentially resulting in further abuse, appears in the work of Howland and Rintala (2001). But in Howland and Rintala's research, as already described, it is accredited to a disabled women's naivety in dating encounters, attributable to a lack of experience. In Lyn's situation, she feels her counter-intuitive responses were embedded within a family history of child sexual abuse, which was typified by a general lack of awareness relating to appropriate physical and sexual boundaries. This theme also appears in the work of Miller et al. (1993) and Herman (1992), with Herman proposing that the woman's minimisation of danger, in clearly dangerous situations, relates to a generalised "dissociative coping style," an issue which will be considered in more detail shortly.

To conclude this section, I need to pick up on the issue of the physiological implications of sexual abuse for a survivor's sexuality, as outlined in May and Jean's quotes. The physical sequel of sexual abuse have, in effect, taken second place to the consideration of the psycho-emotional consequence of sexual abuse, with a tendency to view unexplained medical symptoms in terms of "somatisation," i.e. the bodily expression of psychological pain. Commonly reported physical complaints by survivors include: chronic pelvic pain, gynaecological problems, irritable bowel syndrome, hip and joint pain etc (Nelson, 2002). Both Nelson (2002) and Berkowitz (1998) advocate for the expansion of research in this area, suggesting a number of ways this can be

achieved. Nelson, in particular, calls for physical investigation and diagnosis, which takes into consideration the parts of the body which were actually assaulted in childhood, with linkage being made between this and adult symptomatology. Additionally, the taking of a more detailed sexual assault history, in the medical context, would also facilitate an understanding and sensitivity to survivor's reluctance to undergo those invasive procedures described by May And Jean.

b. Narratives of fragile and fragmented childhood identities

Having focused on adult collective identities, it is now time to turn to the experiences of the individual sexually abused disabled child. Building on the latter section of Chapter Three, and some participants' perceptions of themselves as a "burden" or "problem," this section deals with the fragmentation of a, sometimes, fragile identity as a consequence of the sexual abuse experience. It also later considers the adult-child's perspective on the position of their mother in the abuse situation. To begin with, however, I illustrate the complexity of the situation faced by sexually abused disabled children who have to try and forge an identity from an impossible starting position:

"One of the things that I discovered during my recovery was this idea about our physical bodies being a piece of evidence of ourselves and that when you're young, and possibly this carries on to some extent, where is the line between my self and my body/mind? If this person is saying to me my body is bad and evil then that's saying I'm evil. The big message that disabled children get, regardless of abuse, is that you are a problem, your body, therefore **you**, are a problem, a disappointment, your impairment/difference or your 'self' has 'ruined' the idealised expectation of parenthood, and the perfect '10 fingers and toes' baby. I felt that very much, I felt the pain that my mother had about what was going on with my body and me, I was causing that pain and there was nothing I could do to change that. I think that disabled children get that message very clearly, and then when you are abused as well, and when the abuse is happening with your physical body, they all just get muddled up into this big knot, which can become huge self hate focused on the body, mind and self. "

Jean

i) Methods of protecting the self during, and in the aftermath of, sexual abuse: “holding my breath”

Participants highlighted a number of issues relating to their childhood identity that were symptomatic of their sexual abuse experience. Survival dictated the necessity to employ a range of behaviours, many of which were used to cope with the experience of sexual abuse whilst it was happening, and others designed to deal with the subsequent confusion and negativity generated by the abuse experience. This emotional pain was invariably internalised and led to the development of a series of dissociative states, which found expression in either dissociative amnesia (forgetting) or the development of a number of self-destructive behaviours (see Chapter One, page 14), which were designed to bring about a sense of control. Additionally, one participant spoke about the externalisation of those feelings and their manifestation in terms of his involvement in criminal activities and football violence. I start with a quote from Lyn who details a commonly reported method, used by children, to psychologically escape the abuse experience at the time of its occurrence:

“At the time, in order to survive the experience, I think I was probably doing a bit of dissociation, because I can remember something like that, though I always described it as ‘holding my breath.’ It was partly physical dissociation from the body, but also, in a sense, stopping time while it was happening, then you could experience the whole thing in a very different way, so it wasn’t part of daily life.”

Lyn

Two participants in this study, who were extremely young when sexually abused and unable to process the event on a cognitive level, dealt with the experience by “burying” the memory or developing dissociative amnesia. These participants spent a significant part of their life contending with psychological symptomatology, such as depression, insomnia, suicidal ideation etc, which appeared to have no definitive cause and sometimes became confused with other issues such as disablism. Here I offer a quote from Lizzie to illustrate this point, but I will deal with the issue of repressed and recovered memory more comprehensively in the next chapter:

"I attempted suicide at a time when I was far away from my family. Things caught up with me then, but I didn't know what was catching up with me. I was 22 and I had no idea what was going on. I think now, I mean even now I'm not entirely sure to be honest, but I was surrounded by children..... Do you know what's just dawned on me, goodness knows whether some deeply unconscious process was going on, years later it emerged that two of the staff who were there when I was there, had been abusing children. Could I have had some kind of radar? I don't know. Or whether it was just being surrounded by children, or whether it was being so far from my support.... it can't just be that, I don't know, I've not yet really worked it out. And again muddled by disability issues, because again the staff were abysmal in relation to my being disabled and the kids were great but there was nobody, absolutely nobody amongst the staff who had an ounce of understanding."

Lizzie

The following range of behaviours reflect a need for participants to express emotional anguish through internalisation of that pain and consequent assaults on the physical body. This took a number of forms and below May and Lyn talk about their experience of anorexia nervosa:

"I cannot remember ever making a decision to stop eating but I remember feeling very unhappy and not feeling like eating. I think one day just stretched into another and I only realised that I had a problem when I wanted to eat and couldn't. I found eating painful and chewing just made me feel sick. Looking back, I think I stopped eating because I was depressed, without knowing it. I think I just got used to feeling unhappy, so didn't realise other people didn't feel the way I did. I can make this judgment now because I have learnt to recognise the signs of my depression, and one of the first things is that I stop feeling like eating."

May

"I got obsessed with my weight at around 15 and stopped eating and I think, from what I've read, that's also very characteristic of girls who've been abused. I can remember that part of the motivation for that was.... It's very complicated, but one element of it was that I wanted to make people worried. I wanted them to pay attention and ask me questions, but I don't think any body noticed that I'd lost weight. I never got catastrophically thin until I was at university and about 19 years of age."

Lyn

Two participants spoke about self-inflicted injury, otherwise known as self-mutilation. In these two cases, the explanations given regarding the purpose of the behaviour differed. In Lyn's situation, she talks again about the behaviour in terms of needing to attract the attention of others to her distress. She also makes the connection between self-mutilation and the discovery of her father's infidelity:

"When I was 14 things started going overtly wrong. Up until then I'd been doing very well at school. I think I was a success story really in every body's eyes, and then suddenly when I hit 14 I started doing self-mutilation. Whether it was a long-term response to Phil and my dad, I don't know, but it was around that time that I found out, and my mother found out too, that my father had been having all these affairs. So it kind of went kaboom! at home, and I responded by starting to cut, for all the reasons that girls do. I think I felt very desperate that nobody noticed that I was very unhappy, and that it didn't seem to occur to any one that I could be doing well at school yet still would be in trouble."

Lyn

For Thomas, the self-mutilation started after his stepfather's death and was precipitated by a need to punish himself for grieving for his step-father and for, simultaneously, holding together two sets of conflicting emotion:

"After his death I continued to live at home for a while but my relationship with my mother was not a good one, and months after he died, then it hit me, and then all of a sudden I started crying, getting weepy about him and missing him. And I thought 'what the hell am I missing him for,' and then I'd get angry with myself for missing him and that's when I started self-injury, cutting and being a prat basically. I used to do my arms quite a lot, can't see the scars so much now, but I was carving swastikas in to my arms."

Thomas

Similarly, drug and alcohol abuse were prevalent in the narratives of several participants. Thomas relates this to his desire to self-destruct following his stepfather's death, and a realisation that his identity had become totally consumed by the sexual abuse experience with no other purpose to his life outside of this:

"I mean now I look back and think 'Christ, how I didn't kill myself I'll never know.' I mean it was like heroin, I can remember the first time I did that, we were all sat round in a front room and they were doing heroin and amphetamine mixed, which is what they called speed balls, and they were going, 'Is anybody here going to have a go?' And I was, 'Oh yeah, pass it here, I'll do it.' And everybody else was worried about what I was going to do and were asking whether I was sure, but I was straight up with the trouser leg, bumf, straight in. And now I can see why: he was dead, I'd got no reason to live anymore, I'd got no reason to hate anymore, so I might as well top my self, who else is going to want me."

Thomas

Three participants (who had not buried the experience) made suicide attempts, and here Josh talks about how the pressure of starting Polytechnic had led to a nervous breakdown and attempts to take his life:

"I had to do the course in 18 months and it was a bad time. I actually missed one of those five terms because I spent most of that time in hospital because of not coping with what had happened in the past. I was in a strange city, I was having a nervous breakdown, I was trying to do a three-year course in less than two years, I mean you're talking about pressure, and I had it. I tried to kill myself a few times because I couldn't deal with it, I took pills and I cut my wrists. I almost succeeded once, I was on a ventilator, I didn't realise I'd been on a ventilator until later."

Josh

Lyn describes how the help she received in relation to her anorexia had created a positivism, which contrasted with the demands and constraints of her family situation. This resulted in a suicide attempt:

"The first year at university, the first part was very happy, then the eating got worse and worse and I started to see a specialist in eating disorders who was at the university that I was at, and that was very good. But ironically enough the therapy made me feel that there was a way out, but my mother was so much pulling back at that point. She was feeling ill, she wanted me to come home every weekend. It got worse and worse and worse and at one point, in the August of that year, I took an overdose. It was not that serious an overdose, but it could have been had I not thrown it up again almost immediately. However I knew enough about drug dosages to know that it wasn't

enough really. It wasn't so much a gesture to other people, I think, as a gesture to myself to say 'this is actually how bad it's got.' "

Lyn

Depression and a sense of isolation resulted, for May, in an unsuccessful drug overdose, which reinforced her sense of futility:

"I also stopped going out all together and at my lowest point took an overdose of my medication. I knew that ten was enough to kill someone, so I took twenty and went to bed thinking that that was the last time I would have to go through that. Obviously I did not succeed and this just made things even worse in my mind, I felt 'how useless are you, you can't even kill yourself.' "

May

Lyn expresses her views about the function of these inwardly directed destructive behaviours:

"I think some of my behaviour then was expression of just pain and self-disgust. Some of it was about being lost and needing to feel in control of something. Some of it was almost a calculated attempt to get people to notice, and not simply for the sake of it, but to actually notice that there was something wrong."

Lyn

For some of the participants, the experience of sexual abuse resulted in symptoms, which were somatic in nature. Josh elaborates further on this issue and feels that his emotional state was reflected in his bodily sensations:

"I mean it was like I had these tight bands wrapped around me and they were holding you in, and I needed somebody to come along with the wire cutters and just cut me free. And then, when that happens you're okay, and that happened to me gradually. I mean up to being 30 years old, before I began to feel better, I used to wear a size 9 shoe, now I wear a size 11; that's how powerful the feeling of being constrained was."

Josh

Not as a consequence of child sexual abuse, but following a rape incident that occurred whilst Lyn was at university (page 134), she, similarly, describes how

the emotional pain related to the incident became relocated, temporarily, in her body:

“What I did was to dissociate to an extent. Physically, I remember I had a sense of my body being an odd patchwork of bits that weren’t quite connected with each other and that lasted until about the November. It happened in June. Until about the November there was the thing that any bit that they did touch didn’t feel quite right, and the only bit that they hadn’t was my left hand and that felt normal, it was very strange.”

Lyn

In externalising terms, Thomas describes how his anger relating to the abuse found expression outside the body in his criminal activities, which he sees as a conscious attempt to attract attention to his situation. Additionally, he describes the violence he initiated at football matches as bringing about some cathartic affect:

“I would get up in the morning and think to myself ‘I’m going to be a bad boy today and I hope that I do get caught, and I hope that the coppers do bring me home, and I hope that you’re shamed and I hope that all the neighbours do see the police car, and see me not giving a toss basically that I have been caught. Make them realise that this local trade union official and labour party chairman has still got this terrible awful son that won’t behave. I’ll bring some shame on you; I can’t stand up in the middle of the street and say this guy is abusing me, but what I can do is make your life a living hell through living with me, through you being in my space.’ “

Thomas

“I mean I often hear it said, especially by that generation above us, ‘Oh they make me sick these young criminals, they go into court and say that they come from a broken home or they’ve been abused and what’s that got to do with nicking a car?’ Well it’s got a bloody lot. It had a bloody lot to do with me wanting to go to Man united matches and kick the complete crap out of a perfect stranger simply because he swore at another team. I used to walk away from that and think ‘I’ve inflicted on somebody what I had inflicted on me and that’s good.’”

Thomas

According to psychoanalytical/psychological theory, the process of identity formation starts in early infancy and through the achievement of a state of “mutual attunement” with primary care givers (Stern, 1977; 1985) creates, by the age of four, an increased understanding of the self and others in the child. For some children, as already indicated in Chapter Three, pages 102-104, this process may have already been interfered with as a result of disability, but the experience of sexual abuse intensifies the interruption of a child’s ability to form a coherent sense of self and successful object relations later on in life (Elliot, 1994). In terms of intra-familial abuse, in particular, the disruption of the parental bond, according to Clark (1993), is what makes sexual abuse such a devastating experience for the child. He argues that this experience invariably signifies a major shift in parental availability, both in terms of the child being unable to comprehend the abusers inconsistent and harmful behaviour, and the loss incurred with regard to the mother’s perceived incapacity to manage the child’s consequent emotional disorganisation.

Putman (1997) contends that it is these patterns of attachment in intra-familial abuse, which primarily produces fragmented versions of the self. The shift in the child’s perception of maternal availability, in particular, often results in the child feeling that the mother is aware of the abuse and is unwilling to protect them, which is occasionally the case. The complexities of this particular topic will be given further consideration later on in this chapter.

The extremes of dissociative behaviour associated with child sexual abuse, which exceed the normal threshold of dissociation experienced by people in general, is commonly defined in the academic literature as “a disruption of the usually integrated functions of consciousness, memory, identity and perceptions of the environment” (Mulder et al., 1998). Dissociative behaviour is a common feature for children who are faced with an experience, which is incomprehensible and who are commonly deprived of any sense of autonomy or control regarding bodily ownership (Provus McElroy, 1992; MacFie, Cicchetti and Tooth, 2001). Dissociation actually occurring during sexual abuse itself, as described by Lyn, is reported by Johnson et al. (2001) in their research with survivors of sexual abuse. This type of dissociation can take a number of

forms but generally involves the induction of an alternative state of being such as self-hypnosis or becoming part of the wall (Gelinas, 1983). It generally makes a transition, over time, from deliberate attempts to psychologically escape the immediate situation to the later development of self-hypnosis as an involuntary response (Herman, 1992).

Johnson et al. (2001) found, in their study, that abuse that involved penile penetration or threats that someone, or something else, would be killed increased the level of dissociation at the time of the abuse. Research also indicates, as does this study, that a child's dissociative responses to sexual abuse can often persist into adulthood. Certain abuse related characteristics such as the age of the child at the onset of the abuse, intra-familial abuse, multiple perpetrators and/or the presence of peritraumatic dissociation, are seen to increase the severity of adult symptomatology (Johnson, 2001; Elliott and Briere, 1992; Gold et al., 1999). What Johnson et al. (2001) did find, however, was that the variance between these characteristics was minimal in terms of symptomatology, indicating, as evident in the research of others (Van der Kolk, Weisaeth and van der Harst, 1996), that the cognitive processing and interpretation of the event can be as significant as the event itself.

A number of perspectives have evolved which attempt to extrapolate the mechanisms at play during dissociation resulting from child sexual abuse. These theories range from bio-chemical explanations, which describe the effect of stress hormones on the sympathetic nervous system, which in turn affect the brain's ability to assimilate the information (Bower and Sivers, 1998), to psychological or psychoanalytic perspective. Here authors such as Young (1992), argue that the child or teenager responds to the impaired or spoiled body by "abandoning it or turning on it in anger." These theories assume that, already in early childhood, the mind has the capacity to keep separate painful information from a developing sense of self (Oppenheimer, 2001). As can be seen from other's research (Briere and Runtz, 1988; Anderson et al., 1993) and participant's accounts in this study, the process of disembodiment or dissociation can take many guises, which will be discussed shortly.

In line with the views of Young (1992) and Warner (2001), I would assert that rather than viewing the consequences of child sexual abuse in psychopathological terms, which has traditionally been the case, many of these behaviours can be seen as constituting a logical expression of pain and confusion by a “healthy child to an unhealthy parental environment” (Summit, 1983). This pain manifests itself as hate and disregard for the body, which is confirmed by the actions of their perpetrators, and is, correspondingly, alluded to in Lyn’s quote. In many instances, these behaviours are a form of protection of the self and one method of holding memories of the abuse experience in an unpredictable and sometimes hostile environment (Anderson et al., 1993).

As can be seen in the narratives of both Lizzie and Jean, one type of dissociative behaviour is amnesia or “burying” of the memory (see Chapter One, page 14), only for it to be recovered in adulthood with varying psychological consequences for the individual. As already indicated, this subject will be covered in some depth in the next chapter. Suffice it to say, dissociative amnesia is argued, by some researchers, to be a relatively common occurrence for children less than two years of age who, in terms of their general development, lack the “neuro-physiological maturation, sense of self and subject knowledge in order to be able to process the experience” (Courtois, 1999). For older children too, partial or total forgetting may also be a feature, with some writers arguing that memory deteriorates as the severity and duration of the trauma increases, so necessitating stronger defence mechanisms (Terr, 1991). Clark (1993) also believes that forgetting or burying is a form of self-protection, with both Clark and Courtois contending that it is generally accompanied, at that time, and later into adulthood by symptomatology with unfathomable causality, as can be observed in Lizzie’s quote. Clark asserts that, despite an apparent lack of awareness of causality in the individual, these manifestations equally have the potential to undermine the individual’s self-coherence, self-confidence and identity formation.

Putman (1997), by drawing on the work of Loewenstein (1991), has attempted to produce a categorisation of dissociative behaviours, with amnesia and

memory problems being classified as a primary dissociative symptom. He views emotional numbing and somatization (as described in Josh and Lyn's quotes) as a secondary response and self-destructive behaviours such as attempted suicide, anorexia/bulimia and self-mutilation as a tertiary response. He theorises that the resolution of secondary and tertiary symptomatology are only achievable once primary symptoms have been addressed. It is to these secondary and tertiary symptoms that I now turn.

Both May and Lyn talked about anorexia nervosa, a condition which is essentially a form of self-starvation and that is frequently accompanied by bulimia nervosa. The analysis of eating disorders, in general, has been prevalent in feminist discourse, with authors such as Orbach (1982; 1993) theorising it in terms of a disrupted feminine identity, where attempts are made by the individual to both conform to and reject the socially constructed female form. Orbach (1993) maintains that strategies designed to control dietary intake in anorexia are symptomatic of the denial of a child's ability to recognise and express their emotional needs within the context of their immediate family, an issue which may have some resonance for both May and Lyn. A controlling family environment, she argues, can lead to the child being denied any significant avenues for protestation, an issue observed in several participants' experiences in this study.

When considering the relationship between child sexual abuse and eating disorders there are a predominance of studies that make the association between the two issues (Smolak and Murnen, 2002; Wonderlich et al., 2001). Eating disorders, as can be seen in this study, just happen to be one symptom amongst many of a dissociative state of being (Brown et al., 1999). Harrt and Waller (2001) found, in their study of 23 women who completed a series of questionnaires and a food intake diary, that whilst there was a strong association between the severity of sexual abuse and the severity of dissociation, there was no relational link between the severity of abuse and the severity of the eating disorder. In fact such authors as Connors and Morse (1993) claim that child sexual abuse is just one factor operating in a multi-factorial model of aetiology, with Harrt and Waller (2001) finding that a

neglectful parenting experience can be more strongly linked with eating disorders developing as a result of dissociation.

In terms of trying to unravel the dynamics at play for a child who is sexually abused and who subsequently develops an eating disorder, little is known about the actual processes that underpin this dynamic. As far as physiological features and oral abuse are concerned, a link is proposed between the difficulties involved in chewing and swallowing food and the consequential development of anorexia (Nelson 2002). May, who did not articulate oral abuse in her meta-narrative, describes the problems she had with eating and chewing but associated her anorexia with depression. Psychological perspectives vary in their emphasis with Young (1993) theorising the body in terms of a container of bad feelings and experiences, with the child attempting, by a method of abstinence, to make the body disappear, with the potential effect of “freeing the mind of intolerable feelings, painful memories and physical intrusions.” Again, I would argue here, that the experience of disability might intensify this process for the individual. Miller et al. (1993) suggest that eating disorders, in a sexually abused child, are an act of rebellion against a sexual experience that has been foisted upon them. Drawing on the work of Heatherton and Baumeister (1991), Miller et al. believe that the binge–purge cycle in bulimia, in particular, may produce a self-induced sense of numbness and a distraction from the overwhelming feelings generated by the sexual abuse experience. In any event, despite causality, the general effect of an eating disorder is to attract the attention of others to the child’s situation, an issue raised by Lyn on several occasions.

Self-mutilation, excessive drug use and attempted suicide, issues raised by Lyn, Thomas, Josh and May, are also frequently cited in the literature (Ystgaard et al., 2004; Moran et al., 2004; Turrell and Armstrong, 2000; Harrison et al., 1997; Young, 1992). These activities can also be categorised in terms of dissociative behaviours that involve attacks or destruction of the “spoiled” body and attempts to numb the emotional pain. During these assaults survivors often report little, if no, physical pain, but instead talk of the creation of a sense of calm (Herman, 1992). Research into these three areas

tends to demonstrate that incidence increases if child sexual abuse has been accompanied by another form of child abuse.

In terms of self-mutilation, Turrell and Armsworth (2000) found, by comparing a sexually abused student group of self-mutilators and non-mutilators, that there is an increased likelihood of self-mutilation if sexual abuse is accompanied by physical abuse in the family of origin, which was Thomas's experience, but not Lyn's. In Thomas's quote, in particular, where he graphically describes an incident of self-injury, he raises an issue which rarely appears in the literature (MacFarlane and Korbin, 1983) and which relates to the possibility of the abused child/adolescent also having a range of other feelings for their perpetrator, some of which may be positive. This perspective is also alluded to in Lyn's narrative, but for Thomas he describes these feelings as being unbearable and punishable by directing this rage at his body.

Similarly, Harrision et al. (1997), in their large-scale, questionnaire-based, study of substance abuse in the general adolescent population, found a strong association between physical and sexual abuse and multiple substance use, which is a relationship also prevalent in Thomas's narrative. They found that adolescents, male or female, who experienced abuse, tended to "use a greater variety of substances, have an earlier initiation into substance use and more frequently attempted to self-medicate painful emotions." Moran et al. (2004), using a similar sample group and methodology, also found this strong association between sexual and physical abuse and substance use. They found male participants significantly more likely to use illicit drugs, which the authors hypothesise might be attributable to sexual identity confusion, generated by the experience of a same-sex encounter. As already indicated, this was a concern for Thomas, but was not raised as an issue relevant to substance abuse. Thomas's quote also highlights the issue of the identity of the sexually abused child whose function/purpose has become consumed with meeting the sexual needs of adults, and whose experience and adaptive behaviours become their reality and influence their view of themselves and their sense of self-worth (Young, 1992; Clark, 1993).

The same association between sexual and physical abuse has also been made in relation to attempted suicide (Ystgaard et al., 2004). Barker-Collo (2001), in her study of women referred for therapy, analysed suicide attempts in relation to attributions of blame made in childhood. She found that women who, as children, were sexually abused by a family member or by a stranger, when less than ten years old, tended to demonstrate self-blaming tendencies as a child and exhibit increased levels of symptomatology and suicide attempts later on in life. This self-blame characteristic is certainly present in May's grand narrative (page 173) and could have had some bearing on her suicide attempt in adolescence. Similarly, Lyn's feelings of complicity detailed in Chapter Three (page 97) could also be relevant. For both Josh and Lyn their suicide attempts occurred at university/polytechnic where they were reliant upon a depleted sense of self to navigate the challenges and pressures they faced in their new environment. Paradoxically, for Lyn, who was receiving counselling around that time, which enabled her to acknowledge her emotional need within the context of a safe adult relationship (Orbach, 1993), the neediness of her family countered the positive effect of therapy, which then led to a suicide attempt. For Josh, the pressures of university life and an emerging personal awareness of his abuse triggered an emotional implosion, which precipitated a number of suicide attempts and associated periods of hospitalisation.

The presence of somatic symptoms such as sleep disturbance and anxiety problems have been noted in the research of others (Rimsza et al. 1988) and are commonly cited problems for participants in this study. Vedat Sar et al. (2004) suggest that conversion symptoms are, in fact, part of complex psychological processes that "extend these transient somatoform symptoms." Conversion symptoms or conversion hysteria are commonly defined as a group of physical or sensory symptomatology with no apparent physical cause. Examples of this phenomenon can be found in the early writings of Freud (1905) and are present in the narrative episodes of both Josh and Lyn, who report both disturbance in sensation and contracture. Roelofs et al. (2002) found that, in their study of forty-five women and nine men who experienced conversion symptoms, compared to patients with affective

disorders, patients with conversion symptoms reported longer lasting incidents of child sexual abuse and a greater incidence of incestuous relationships. Again, conversion symptoms, I contend, are also a form of dissociative behaviour whereby the emotional trauma is housed in body parts, so protecting the “self-system.”

Finally, it is necessary to address the displacement of the hate and anger, generated by the sexual abuse, into the wider environment. In two of Thomas’s quotes he speaks about this expression of anger in terms of his criminal activities and his violence at football matches. The former activity he relates to his need to bring attention to his situation, and the latter to his need for some type of cathartic release. Some research refutes a relationship between an increased involvement in criminal activity and a history of sexual abuse (Spatz Widom and Ames, 1994). Others research makes a relational link (Swanston et al., 2003). By comparison to a control group, and in a sample of ninety-nine sexually abused children, Swanston et al. argue that child sexual abuse is a strong predictor of subsequent involvement in criminal and aggressive activities for both males and females. When utilising a number of measurements, including child self-reporting, and adjusting for a number of variables such as age, sex, socio-economic grouping, the authors noted the prevalence of crimes such as assault, malicious damage to property, break and entry, theft etc, all of which Thomas describes in his grand narrative account. Unlike the findings of Chandy et al. (1996), who demonstrated a gender differential, with male participants being more likely to turn to crime and females demonstrating a higher propensity for internalising behaviours, Swanston et al., by contrast, found no such relationship. They reported, instead, that both male and female children as equally likely to engage in criminal behaviour.

ii) Perceptions of missing allies: “your father is your special friend”

Within this section I will be addressing the issue of the child’s perception of the safety of their immediate environment in cases of intra-familial sexual abuse. Central to the operation of perpetrators sexually abusing children

within the family context is their capacity to isolate the child from possible avenues of support, including other siblings who may also be experiencing abuse, and more crucially the child's mother. Such strategies facilitate an individualising process whereby the child feels somehow responsible for the abuse, and perceives the non-abusing parent as complicit by failing to see the child's distress. All participants in this study who had siblings were unaware, as children, that some of these siblings were also being abused. Additionally, perceptions of their mother's position varied from suspecting that they must have known about the abuse yet failed to act, to being absolutely certain that this was the fact. As detailed in Chapter Three, pages 102-104, for some, the disabling attitudes of parents were already part of the equation and may have influenced the child's sense of safety. The following quotes vividly illustrate the child's perception of the non-abusing parent, from their adult perspective:

"It was one Tuesday night that, in my mind, confronted my mum with the truth. It was just before my seventh birthday: September 1974. We had started back at school that day after the long summer holidays and as always she had gone to bingo. Dave who was twelve was out with his mates and not due in until later. He raped me and beat me, but before I had the chance to wash and dress in walked mum, she had forgotten something. So there I am in the living room, naked and bleeding from my anus, how would he get out of this I thought. He told her I was constipated from drinking too much milk. He told me to bend over and said that I came down from the loo like this and that he was going to clean me up. I just stood there, and out of fear of not being believed I said nothing, even when he left me and mum alone and went to the bathroom to fetch the Germalene, I said nothing. To this day I wish I had but fear prevented me. She applied the cream, said that I wasn't allowed any more milk and went back to bingo. She must have known that there was more to my injuries than constipation, she had to, what kind of mother can apply Germalene to a boy's backside believing those injuries were caused by constipation!"

Thomas

"I know that my mother must have seen a considerable amount of what was going on, and apart from a couple of one sentences like, 'Leave her alone,' I don't remember her intervening in any way. I have been very resentful of that. I wonder now whether she actually went through something whilst she was in the children's home, because you read so much now, you hear so much about abuse within children's homes. She had very difficult relationships with men when

she was an adult and I suspect that something may have happened to her that made her totally unable to deal with it. Or perhaps she just simply took it for granted: that it might have seemed more normal to her than other people.”

Lyn

“When I got to the age of nine/ten my mother suspected something because one day she came up stairs.... I mean this is how crazy it was getting, she was actually in the house and came up stairs, and I think I’d been ill, and it was the afternoon and I was ill in bed, and so she came upstairs. So he leapt off the bed, but of course he had left his belt on the bed, I remember that belt, I had been hit with it. And so she started to get a bit suspicious and then when I was eleven, and this is where they ruined my education really, I was about to go to secondary school, I was going in the middle stream, the “B” stream, which was fine, but they decided to send me away to a special school for people with disabilities.”

Josh

May’s situation differed in the respect that her mother knew about the sexual abuse and even acknowledged it with May, so increasing May’s sense of culpability and worthlessness:

“Things had been happening to me for some time when one day my mother told me, ‘Your father is your special friend.’ At the time I thought she meant I was being treated differently to my siblings, but a few months went by and then out of the blue, my mother told me she could hear everything. I then thought back to what had been said earlier and realised she had known all along. This made me feel ‘what is the point in saying anything, she doesn’t care what happens to me.’ I am sure my mother felt that it was my fault and that it was better than my father having an affair outside. It also meant that she didn’t have to do things that she didn’t want to, like having sex, which she told me she was not interested in, but kept the financial security. I started to think about the things that had happened and realised not only did my mother know, she also created opportunities for it to happen by going out all day, making my youngest sibling go as well even when they didn’t want to.”

May

Whilst acknowledging the difficulties surrounding a researcher’s ability to understand the internal dynamics of individual family situations (Baker, 2002), I believe that some of the major research findings relating to the position of the mother may have some relevance to the experiences of Thomas, Josh,

Lyn and May. The motivation to explore this subject area further rests in the necessity to illustrate the importance of the child's perception of their immediate environment, since, as can be seen in Chapter Three, pages 102-104, it determines a child's ability to speak out about the sexual abuse. It also affects, ultimately, the child's self-esteem and sense self-worth, with the repercussions carrying into adulthood. The four participant's quotes illustrate a range of perceptions experienced by the child, ranging from a degree of suspicion that the non-abusing parent was aware of the situation (as in Thomas, Josh and Lyn's case) to absolute knowledge of the fact, demonstrated by the mother's admission (as in May's case).

The role of the mother in cases of intra-familial child sexual abuse has again been the site of conflict between psycho-pathologising and individualising models of personal dysfunction (Baker, 2002), and broader sociological perspectives. Family systems approaches, for example, propose a circular causality (Hooper and Humpherys (1998) and feminist approaches depersonalise the problem and attribute it to power relations and the societal construction of the family, which places unrealistic and unobtainable expectations on the mother (Bell, 2003). For feminists, and as already indicated in Chapter Three, pages 91-92, child sexual abuse is one manifestation of male dominance, with feminist readings highlighting the processes of maternal disempowerment. Hooper and Humphreys (1998), whilst appreciating the importance of incorporating an understanding of the societal context, feel that feminism's broad based analysis can sometimes negate necessary theorisation of the complexities of the individual experience. In response, they propose an integrated model, which is based on Finkelhor's four preconditions (1984) referred to in Chapter Three, page 92.

Both Hooper (1992) and Bell (2003) have established that it is possible for a mother not to be aware of the ongoing abuse of their children by perpetrators living in their home. This fact is supported by the reality that often the abuse occurs in their absence and that the child is often coerced into secrecy using psychological tactics or overtly aggressive means described in Chapter Three, page 95. Additionally, Hooper also demonstrates that some mothers may also

know about their children's abuse, as was the case for May, and fail to act for a number of reasons.

In Hooper's study (1992), which involved interviews with fifteen mothers, the issue of mother's knowledge relating to their child's abuse was explored in some detail with children "thinking their mothers knew when they didn't and also thinking that they didn't know when they did." For the mothers who did not know about their child's abuse, most were actively involved in a process of re-interpreting their partner and their child's behaviour, with sexual abuse not even being a consideration. This could, in fact, have been the situation for Josh's mother in the early stages of his sexual abuse, since Josh describes her, in other parts of his narrative, as being, essentially, a naïve person. Five mothers in Hooper's research were pre-occupied with surviving violence and the erosion of their own self-esteem within the context of the parental relationship. One mother was desensitised by her own childhood experience of sexual abuse, an issue raised in the research of others (Paredes et al., 2001; Oates et al., 1998), and which could have possibly been the case for Lyn's mother. One woman lacked confidence in her own parenting abilities and another adopted a detached and non-confrontational approach to family life, which could have been the case for Thomas's mother, who was mothering within an overtly violent familial context.

Women who suspected sexual abuse had to grapple with a number of issues including the problem of differentiating between abusive and non-abusive interactions between the child and the abusing adult, which created an ambiguity that impacted upon their ability to make interpretations. This too could have been the experience of Lyn's mother, whose husband abused within a context of the confusion he created in the minds of others, including Lyn. Additionally, the women in Hooper's study were confronted with relationships, with both the child and the abuser, of varying quality, which determined their ability to confront either, or both of them. The process of constructing a reality for these mothers often took a significant period of time and was located in a context of guilt regarding the question of having these

suspicions, in the first instance, and their ambivalence about what knowing would mean for them and their children.

For three mothers in Hooper's study there was confusion about what could be considered to be a sexually abusive act, and that sexual abuse was, in fact, a misuse of adult power with detrimental consequences for the child. Hooper related this to the women's subjective sense of powerless in their own lives. This lack of insight skewed the mother's ability to see through the justifications of one abuser who chose to interpret his behaviour as non-harmful sex education. It also caused them to misinterpret their daughter's reluctance to talk about her experience of sexual abuse as her enjoying the experience, and it created confusion with regard to the relationship between abuse and pleasure. For these three women the children were seen as complicit and equal partners in the abuse, with one woman seeing her daughter as a seducer and the other two showing little concern for their children's well-being. Clearly, some of these themes are relevant to May's experience, particularly her mother's ignorance to the fact that her husband's behaviour constituted child abuse, and also her disregard for the devastating consequences of his behaviour for May.

Bell's research (2003) was based on interviews with eleven women who were living with the perpetrators at the time of their child's disclosure. Of the thirty-four children born to the interviewees, seventeen disclosed abuse: five when they were under five-years old, four as teenagers and two as adult children. Five interviewees also discussed unconfirmed suspicions of sexual abuse in their other children. Unlike the findings of Hooper (1992), all the mothers in this study described the child's disclosure as a great shock, which necessitated a significant reappraisal of the mother's maternal identity. All these women described themselves as having a close relationship with their abused child, with some describing their partners' deliberate attempts to sabotage this relationship, an issue also referred to in the writings of Hooper and Humphreys (1998). This positive mother-child bond, however, which failed to facilitate a child's disclosure, was the most difficult aspect of the abuse to accept. Similar to the views of Hooper, Bell also problematises the

concept of knowing, with her arguing that “ongoing child sexual abuse is embedded within complex relationships whose outward appearance does not always reflect the abuse.” She also makes the point that “the reason why they don’t see may be related to the fact that what there is to see varies greatly.”

In her analysis, which is largely embedded in feminist discourse, Bell (2003) acknowledges the fact that often a mother’s failure to detect abuse attracts as much hostility, by others, as the abuser’s actions. She problematises various aspects of society’s notion of the “perfect mother” and identifies the ideals embedded within this concept, believing that they placed the mothers, in her study, in an untenable position. In particular, she discusses the concept of “motherhood as power” and proposes that this issue of power, in relation to the power to protect, is an illusionary concept within a patriarchal society that dictates its family structure and organisation. Many of her interviewees, in the first instance, felt powerless to protect themselves from domestic violence, let alone their children from abuse, which may have possibly been the case for Thomas’s mother. In addition, the notion of maternal selflessness, which prioritises the needs of others, particularly males, resulted, for many participants in her study, in the toleration of domestic violence, which she proposes provides a role model for female behaviour that can then be mirrored in the child’s tolerance of the abusive relationship.

The findings of other researchers, who have investigated the impact of children’s disclosures of sexual abuse on the mother’s own self-perceptions, may also have some relevance to participant’s experiences in this study. In particular, I note the research of Bernard (2001) who investigated the experiences of thirty black mothers whose children had experienced either intra-familial or extra-familial sexual abuse. Bernard raises the issue of “stigmatising deficit models of motherhood” where racist stereotypes of promiscuity, in this instance, were prominent in the mother’s mind. These stereotypes compounded their negative perceptions of themselves, and influenced their preference for seeking support from family and friends, rather than professionals. Similar issues must impact upon a disabled mother’s

ability to “see” and “act” where there are suspicions of child sexual abuse. These factors could have possibly been prevalent for Lyn’s mother.

In concluding, however, I return to the work of Barker (2000) who contends that, in reality, the mother’s validation of survivor’s disclosure is one of the most essential elements in their future healing process. Only after this has happened are survivors able to stand back from their personal experience and consider any sociological or psychological interpretation of their mother’s position and actions. Others, by contrast, might refute the importance of maternal validation for future healing.

c. Concluding remarks

Following on from the previous chapter where a number of participants described how the impaired body had interfered with the bonding process and parenting behaviour, this chapter has dealt with how sexual abuse further corrupts the developmental sequence for the child, by creating confusion in relation to the safety of their childhood environments. Both of these experiences, but childhood sexual abuse in particular, compromise the child’s ability to situate the self as a social being (Crowley, 2000) and ultimately differentiate the self by moving to an “I” position and functioning in an autonomous manner (Johnson et al., 2003). By employing a psychological perspective, I have argued that, in order to deal with an incomprehensible situation, participants employed a number of dissociative strategies to protect their inner integrity or sense of self, as they understood it. These strategies involved a disengagement from the body, which was the site of unwanted adult sexual intrusion, and involved either amnesia or a violation or mutilation of the body, which had become the container of unbearable emotions. Additionally, for some, these emotions were also held as conversion symptoms or externalised through involvement in criminal activity. It is proposed by some, myself included, that the process of dissociation secures the development of the self-system by refusing to integrate the experience of sexual abuse (Oppenheimer 2001).

I believe that participants accommodated, as best they could, their experiences and integrated the consequential effective behaviours into their identity. This process of accommodation created a number of difficulties including: a sense of loss of an identity when the perpetrator died, and the feeling of abandonment experienced when their perpetrator started having affairs. Similar to the views of Blumstein (2001), I argue that these outwardly worrying behaviours/identities of the sexually abused disabled child, which are designed to protect the self, have little to do with the underlying constituents of the real self. The real self strives to find some element of control even if this involves turning upon the body in a self-destructive fashion. Drawing on the work of Jenkins (2004), who argues that these early identities are less malleable and more resistant to change than identities acquired later in life, I would argue that this is the reason why participants subsequently spent a protracted period of time emotionally integrating the experience and trying to challenge the resultant intransigent belief systems. For those who had buried the memory because the abuse occurred at a developmental stage when they were unable to cognitively process the information, the somatic and inexplicable self-destructive drives, created an ongoing lack of coherence in their identity and narrative, an issue which will be given further consideration in the next chapter.

Throughout childhood, adolescence and adulthood, and through their interactions with their wider environment, participants have acquired a number of collective identities, some of which have been claimed with great pride, and others which have been resisted because they are seen to be too limiting or stigmatising. An example of such is the “survivor identity” where the identity has signified both strength and courage, but also, by some, is seen to be too limiting or just another stigmatised label to be added to other stigmatising labels, such as disability. The disability identity has also been dealt with in differing ways, with some individuals drawing upon its political substance, to positive affect, and others recognising how this socially devalued identity has impacted in terms of internalised oppression. One participant described how he dealt with this identity by problematising notions of physical perfection.

Participant's sexual identity has raised some pertinent issues in relation to the interaction of impairment, gender and sexuality. Here the female form, in particular, has been ascribed an objectified asexual identity, which was reflected in parental neglect of their sexual development, their problematic dating experiences and the threat of violence later in life. The additional child sexual abuse experience has created complicating factors relating to: the questioning of sexuality (primarily male participants); the need to provide cover-stories for any potential pregnancy; difficulty in identifying and avoiding risky or violent situations or relationships; problems in enjoying intimate relationships and the adverse effect that it has had on an individual's ability to tend to their sexual health needs. For many participants, and by association, the survivor identity has conferred a problematic sexual identity. In essence, it can be seen that participants in this study occupy multiple identities, many of which are situationally determined, to positive or negative effect, and that not infrequently tensions arise between these identities (Vernon, 1999; Appleby, 1994).

In terms of the theoretical positioning of this chapter, I make reference to the words of Callero, since I believe that they encapsulate the essence of this chapter:

"Admitting to the constructivist nature of the self, recognising its cultural and historical origins, and accepting the self as a product of power relations does not necessarily remove the self as an object and force in society.

Callero (2003, page 128)

Within this chapter, and despite reference to psychological/psychoanalytical theory and their associated processes, I have employed a social constructionist perspective that argues that identities are constructed through interaction with the social world and the power relations that operate within. Similar to Burr (2003), I contend that, within a western society, there are a limited number of possible templates for the construction of identities. A male-privileged, white, non-disabled, heterosexual identity forms the "societal norm" from which individuals are perceived to deviate. As described in a number of

other chapters, these power relations create the notion of the “other” and by doing so push certain identities, such as disability, to the margins of society, where an individual may then struggle to construct a self-enhancing and self-empowering identity. From this position the choice incurred involves an acceptance or rejection of these, often, stigmatised identities. Consequently, this chapter rejects the determinism implied by overtly poststructuralist perspectives, where identity and the self are perceived to be fluid and temporary concepts constructed through discourse and the operation of power. Instead, as demonstrated throughout this chapter by all of the participants, it argues for the embodied and reflexive self who acts with agency to resist societal oppression. The continual telling of one’s life story in differing arenas, an issue which I will be considered in the next chapter, in turn, reinforces an individual’s identity and sense of self (Bruner, 1990).

CHAPTER FIVE: NARRATIVES OF THE NARRATIVE

This chapter builds on the last chapter. It addresses the issue of narrative and how, because of the experience of sexual abuse and the consequent necessity to protect the self-system by a process of dissociation, participants were compromised in their ability to produce an authentic narrative of the self both at the time of the abuse and later on in life. The process of storytelling, generally, requires a sense of the past (Plummer, 1995) and since most participants had spent significant periods of time “not being there” the usual developmental process concerning narration of the self had become undermined. At various points in participant’s lives, when dissociative defences were less critical for survival, they were able to emotionally re-engage with the experience of child sexual abuse. This was either because an incident or circumstance triggered the recovery of a buried memory, or a life event drew the issue more solidly to the forefront of the mind. The necessity to integrate the abuse experience into a personal narrative has been a painful process of varying duration for most participants and initially created personal mayhem and, sometimes, a total emotional breakdown. Reconstructing and re-interpreting the life story was achieved using a plethora of methods, which will be expanded upon shortly. In essence, it has enabled participants to gain greater self-understanding, establish a relationship with the self and, consequently, narrate the self in more comfortable terms.

As I have done in the previous chapter, I will commence with a consideration of the current and ongoing work being undertaken by participants and, then, working backwards, chronologically, I will examine the point at which participants actively engaged, or were forced to actively engage, with their life history in an attempt to create some improvement in their general functioning. In the final section I will consider issues relating to the credibility of the abuse narrative, for others, particularly the recovered narrative. Finally, before proceeding, I need to state that this chapter concerns itself, ostensibly, with the reconstruction of the abuse narrative, which has been influenced, to a lesser degree, by disability.

a. Narratives of work in progress

As indicated, a continuing preoccupation of participants is the reconstruction of a narrative that is both reflective of their situation in childhood and contains a “narrative truth” as defined by them selves. Additionally, for some, the work has also included a recognition of some of the major losses they have sustained through the abuse experience, particularly the loss of “childhood” and the loss of “self.” In some cases, reparative work has been undertaken with attempts being made to put themselves back in their own narrative. I commence this section with an exploration of the reconstructive process and then move on later to consider some of the losses that participants identified.

i) Co-constructing and rewriting the story: “that memory actually makes no sense at all!”

Multiple and combined methods of narrative reconstruction have been used by participants to understand the events of childhood and facilitate the production of more reflective and empowering life history account. Of particular significance has been the role of psychotherapy and counselling, which has enabled difficult information to be voiced, validated and mutually re-interpreted and has, sometimes, included the constructive challenging of specific memories and the belief systems embedded within them. Additionally, the sharing of information with abused adult siblings and/or members of the immediate or extended family has offered other perspectives to the story and, by doing so, has depersonalised the experience to some degree. For one participant, documented material, in this case medical records, has provided external support and corroboration of the personal consequences of their abuse experience. In total, these avenues, which I will now consider individually, have enabled participants to re-build a picture of family life, re-examine their abuse experience and the behaviours of the perpetrator, and co-construct alternative interpretations of events.

The quotes that appear below, from May and Lyn, illustrate two different functions of psychotherapy for individuals who have been sexually abused. In May's situation, the simple confirmation of where blame lies has created the potential to enable her to construct a different type of meaning and corresponding narrative account, which is not shrouded in guilt and responsibility. In a similar vein, Lyn talks about how the therapeutic encounter can serve to analyse memories, locate their origins/purpose and challenge the faulty belief systems that have ensued:

"One time when I visited (after I moved out) I was alone and he kissed me, like you would kiss a partner, and said, 'We haven't done that for a long time.' This made me even more nervous because I was then frightened of him visiting me in my own home as I felt the same things could happen there. At that stage I was 31 and hadn't lived at my parents for a few years. I was so upset that I told my counsellor and she said, 'That isn't your fault, it's him,' but I still felt I must have done something wrong."

May

"One of the most striking things for me about doing therapy and looking back over my childhood, in particular, is exposing the stories and explanations which I had been repeating to myself for many years and bringing them out into the light of day and thinking 'that actually makes no sense at all' but I had never questioned it as an explanation. Having to talk about it and having somebody sitting opposite me saying 'do you really think that' and having to remake the story and think about where that story came from and why it was necessary, who gave it to me, or why I produced it. Those stories can be so powerful and so convincing and yet actually very wrong either in terms of objective chronology or people's motivation."

Lyn

Information from family members has also broadened the picture and helped facilitate a clearer understanding of family life. In particular, it has enabled the production of an extended version of the biography of the perpetrator. In this next quote Josh talks about the varying avenues, which have enabled him to piece together information, expand his own narrative and contribute to other family member's healing:

"I don't know at what point but I know that probably my two younger brothers were also abused because one got very upset many years ago and he wouldn't discuss it, which is fine. But I think that they were only abused once or twice at the most. But then my stepfather's own natural daughter, one of the second lot of twins, has talked openly about her abuse and I helped her a great deal with that about ten years ago."

Josh

"And I mean this is interesting, I didn't know this at the time but it must have been one of the times when my mother was away convalescing and I reckon my oldest sister was probably about fourteen. And I didn't know this at the time but he was taken to court and he was sent to prison for 3-6 months for attempted rape on my eldest sister. And it wasn't something that was talked about but she'd had to run into the toilet and climb out the window and then, after that, she went to live with some neighbours across the road so she was removed from it. And that was obviously around the time that I was being abused but my sister never talks about that at all."

Josh

"I know he went on to abuse children in the family that he went to when he left my mum because I was told. It was the woman he left my mother for, her daughter, she was probably about 14, 15 at the time and he abused her. It came through my youngest sister, not the sister who was abused, and I think she bumped into this girl at one point and had this conversation."

Josh

In a similar manner, Thomas has managed to co-construct a narrative via discussion with his stepbrothers and stepsisters some who have been abused and others who have not. Here Thomas talks about the knowledge he has gained about his stepfather's previous family:

"He'd been abusing his son and daughter from that first relationship. David, his son, who lived in Devon, told me that my step-dad had abused him. He didn't say how, he told me in the mid 1980's. David was really seriously ill with a kidney problem and my step-dad wanted to keep going down to visit him and one day when I'd gone down to see him he just snapped and said, 'I don't want him here,' and I said, 'well, why don't you want him here, why don't you want him down here?' And then he just said, 'Look, what he did to me, as a kid, should never happen to any kid' and that was it, he left it at that. My stepfather and his first wife had also adopted a child called Christine

and it's a very interesting story because...and I've been told this on very good authority from a relative on my dad's first wife's side of the family, that Christine was, in fact, a product of an incestuous relationship between Jack and his daughter Anne. Christine died of meningitis when she was six."

Thomas

By contrast, May discusses her fear of raising the issue of sexual abuse with her younger sibling who she suspects has also been abused:

"Also, there is part of me that is scared because from time to time things happen that make me wonder whether these things only happened to me. My youngest sibling has some of the same issues with men; she steers clear of them. She lacks self-confidence; always going along with what other people want even when this is unreasonable. She has a bad body self image despite being very thin: she always trying to loose weight. I just could not bear it if my keeping quiet meant that someone else had gone through the same."

May

Within the next quote Jean illustrates how, in addition to her mother's information regarding her first period of hospitalisation, the contribution of medical records has led to an ability to feel more confident about the content of the narrative that she is in the process of constructing:

"My mum's information has helped me with the reconstruction of my story. One other piece of the story would be medical records. I got my records from my GP and there were a few bits of information in there that helped and gave a time structure to it. I had an examination with a consultant. It was at a time when my symptoms were fairly mellow so it was just a check up (where I would go and usually wait for about four or five hours and then have an x-ray and blood test and then someone would come and bend my legs in painful ways and umm and ah and then go away and then say come back in another two months or three months). On one of these, kind of, hospital visits I noticed that there was a note made on the records that said something like 'this child seems unreasonably frightened by the medical examination.' So one of the consultants did notice how freaked out I was when he was examining me, although nothing was done about it. There are a few other bits of information like that in the records that helped to validate things and give a bit more structure to the story of what happened."

Jean

It is felt, by many academics, that memory of life events are held in a narrative format (van der Kolk and van der Hart, 1991) and imparted through a process of story telling, which provides a meaning-making function for the individual and listener (Bruner, 1990). Consequently, then, it seems logical that when the narrative has been suspended and distorted by something like child sexual abuse storytelling becomes the obvious method employed to explore the trauma memories and establish a sense of narrative coherence, narrative continuity, and, ultimately, a narrative identity. The co-constructed narrative used by participants in this study, and described within this section, reflect a multi-dimensional attempt to examine memories and gather together alternative accounts from differing perspectives. Through this extended communication structure, it has been possible to facilitate the production of a more comprehensive version of the abuse-story. The re-telling of that story, which happens most typically in counselling and/or therapy, facilitates, by the continual revisiting and re-interpretation of the experience, the co-creation of a story that makes sense to the narrator (Jacobsen Wren, 2003). In the long-term, it enables the integration of that event into the grand narrative account (McLeod, 1997).

As already indicated, most of the participants had experienced counselling/therapy at some point in their recovery process, and, at the time of writing, others are still involved in this work. In terms of narrating the self within the therapeutic encounter, McLeod (1997) draws a distinction between traditional “foundational” or “constructivist” therapeutic approaches, which utilise storytelling to gain access to the individual’s emotional world and the emerging “constructionist” approaches, deriving from these. Here postmodernism forms the underlying philosophy and the client’s process of narration constitutes the clinical currency. I would tentatively assume that most participants, in this study, who accessed therapy, have experienced therapists who utilised a traditional “foundationalist” approach. Lyn’s reference to therapeutic work, however, which calls to question the historically constructed stories that inform her current belief systems could indicate the opposite for her.

Jacobsen Wren (2003) argues that, for individuals embarking upon therapy, it is important to illicit what factors and/or belief systems act as barriers to that person's ability to create meaning and establish "a narrative point of origin" for current difficulties. Simon (1998) writes that, initially, many survivors of sexual abuse are constrained by their state of "entrapment" where a circular self-deprecating belief system operates, perpetuating and reinforcing the issue of self-blame. This state of entrapment, Simon argues, is created by the perpetrator who has given the child a contradictory and immobilising set of messages relating to: the legitimacy of their actions, the enjoyment that the child is perceived to feel, the blame that the child should shoulder and the secret that is essential to keep. Additionally, on a wider level, Burke Draucker (1992) posits that this self-blaming belief system is often fed by the negative "societal prescriptions" relating to female sexuality and the associated locus of responsibility. As discussed in the previous chapter, this state of entrapment may be reinforced and intensified for disabled children by the internalisation of disabling notions of the impaired, therefore bad, body.

Accordingly, both Simon (1998) and Burke Draucker (1992) highlight the importance of positioning the therapeutic encounter within a philosophical context with the necessity to demonstrate a "moral-driven" position in relation to the abuse. Simon states that the harbouring of any feelings of blame (the narrative point of origin), in most cases, needs to be met early on in the therapeutic encounter with a clear statement in relation to the immorality of child sexual abuse. This issue is encapsulated in the substance of May's quote.

For Burke Draucker (1992), the ongoing concern of counselling/therapy rests with an imperative to challenge the self-blaming belief system of the individual, re-emphasise their status as a child in the original experience and guide the development of a new and more reflective belief system so facilitating, eventually, the cognitive reframing of the abuse experience. White (1993) refers to this process as the facilitation of an "externalising conversation" or a "counter-language" where the "internal story ceases to speak to the individual." In that sense, the therapist can be seen to be

responsible for, what Crossley (2000) refers to as, the “master narrative” and the facilitation of a different type of discourse, which extends the individuals understanding of the issue.

The therapeutic process of itself, and as indicated by Lyn, aims at the joint deconstruction and re-construction of a narrative, within the context of a safe and structured environment. This involves the substitution of incompatible childhood stories for the “correct” story (Evans and Maines, 1995) that can then be told to others outside the therapeutic context. According to McLeod (1997, page 119), the process of deconstructing the survivor’s narrative, within the therapeutic encounter, can take a number of forms including:

- The therapist attempting to incorporate the individual’s story into the therapeutic approach, which then gives the story greater immediacy. An example is the use and interpretation of transference in psychodynamic encounters (see Chapter One, page 14).
- The therapist drawing attention to the way the individual constructs their story, with an invitation to consider other ways of telling that story.
- The therapist asking questions that lead to the individual discovering inconsistencies in their story.

Clearly, Lyn’s therapy draws from all three of McLeod’s points. She is encouraged to dissect her stories and consider the validity of their content and the belief systems that ensue. She is also invited to think about other, more accurate, storylines. Later, in the following section of this chapter, it will become obvious that this therapist’s work is also embedded within a psychodynamic framework. Here, part of the narrative re-constitutive process involves the use of the transference dynamic. Regardless of the therapeutic approach, however, one successful evaluative measure of the co-constructive process is the achievement of narrative coherence where, as referred to in the

previous chapter (page 123), there is some connection made between internal feelings and external presentation.

The issue of the accuracy and the importance of recollection will be picked up and debated later on in this chapter but, in therapeutic terms, the overall procedure strives for the achievement of a “narrative truth” or what Spence (1982) refers to as “narrative fit.” Essentially, both of these concepts describe the production of a construct that allows the past to be viewed in a certain manner yet is flexible and robust enough to accommodate contradictory pieces of information. For both Spence (1982) and Bruner (1990), narrative truth is reflected in the individual’s ability to produce a meaning that brings about the potential for change.

For participants in this study who had siblings and who experienced intra-familial abuse, the sharing of information between siblings and the acquisition of additional factual material from within the wider family context has been an important part of the narrative re-constructive process. In Josh’s case, his own bravery and ability to “speak out” has prompted another abused sibling to take a similar risk. The barriers to adult disclosure (an issue which has been partly discussed in the previous chapter, page 124-125) are well documented (Arata, 1998) and generally centre round not being believed. The first disclosure, within a sibling group, can often have variable effects. Responses can range from other siblings also feeling compelled to disclose their abuse as well, to a denial and re-burying of the secret by other siblings (MacFarlane and Korbin, 1983), which appears to have been the case for Josh’s brothers. MacFarlane and Korbin contend that this denial, in some instances, may be located in the guilt experienced for “allowing the abuse by keeping their silence” an issue raised by May. Whilst disclosure for both Thomas and Josh has been a growth promoting experience, which has facilitated the production of an authentic narrative, for some of their siblings disclosure may be too painful at this particular moment in their life.

I believe it is worth considering briefly, here, the function and maintenance of family secrets from a cultural and family systems perspective. Not

withstanding the numerous barriers that sexually abused children face when contemplating disclosure, it is helpful to consider, briefly, why these secrets continue to be kept within the family unit well into adulthood. Vangelisti (1994) believes that the function of family secrets, such as child sexual abuse, which transgress the social and sexual rules of society, is to protect the family structure and family members from societal disapproval and, ultimately, prevent family breakdown. In essence, they are an extremely powerful mechanism for perpetuating an exterior illusion of familial cohesion.

Crago (1997), who claims that secrets replicate themselves across generations, argues that the thinking generated by family secrets that involve a societal taboo is similar to “magical thinking.” There is a belief that the raising of the topic, even in adulthood, will either make the situation worse or risk personal alienation from the family. He believes that secret-keepers feel that, by keeping quiet, they are “protecting others from information that will somehow harm them.” The anxiety created for secret-keepers in their quest to remain silent, according to Karpel (1980), is generated by a fear of inadvertent disclosure and their discomfort when relevant topics are ever discussed. Some of these dynamics may have some relevance for participants and their siblings in this study.

One other source that contributed to narrative re-construction, and which provided a corroborative function in one participant’s process, was the use of medical records. Since the introduction of the *Access to Health Records Act 1990* doctors are now invested with a legal obligation to facilitate unrestricted access to patient’s medical records (Brazier, 1998) with an accompanying ethical obligation to ensure that the patient understands what they read and are supported in the process. There are cases cited of adult victims of sexual abuse returning to view their medical notes in order to establish whether or not the medical profession had known of their sexual abuse (David, 1998) but I am unaware as to whether this was the intended purpose for Jean. What the process did achieve, however, was an externally located source of substantiation, and hence validation, for her recovered memories (Ross and Buehler, 1994), which offered a time frame for her narrative.

ii) Acknowledging and re-working the loss: “my childhood was nicked”

Part of the process of “storying the self” has involved an acknowledgement of the parts of the personal narrative that have been eroded or, at the very least, severely tampered with. Some participants spoke of narrative loss in terms of “loss of childhood” and others spoke about the “loss of self.” In varying ways, and through the process of healing, a number of participants have attempted to actively reclaim some elements of their narrative, if only symbolically, and acknowledge that other aspects of their healing may be an ongoing process. I will start here with quotes from Thomas, Josh and Lyn who talk about the loss of differing aspects of their childhood:

“My stepfather also stole Christmas day from me since too much wine at lunchtime led to my mother having to lie down and sleep it off leaving my stepfather to fulfil his needs. ‘Happy Christmas son,’ was what he said as he left the room with a smile on his face. When I think back to that afternoon that’s when I know how much I lost as a child.”

Thomas

“My childhood was ‘nicked,’ it was stolen, I was thrust into an adult world before I ever should have been, it went, it was gone from the age of five or six, so now I’m trying to make up for it.

Josh

“He stole my childhood and he stole it pretty early on. An introduction to sex and sexuality should happen naturally, it shouldn’t happen at a forced pace, and I should not have been used as a rag doll. I should not have been used for someone else’s pleasure at that age, and nobody should, and it took me a long time to get over it.”

Josh

Lyn speaks specifically about a particular developmental period and how the usual process of pushing familial boundaries was denied because of a need to provide structure for her parents:

“Looking back on it, I had a really contained adolescence and it was easy to blame that on the disability but I don’t think that was all that it was. My mother was very protective. It was very easy for it to be said that the reason that I didn’t get out more, and didn’t, apparently, want

to get out more was because I didn't hear well, I was shy, it was difficult, and all the rest of it. I think it was more that I was the one who was providing structure in the family. I wasn't going anywhere. The fights that you have with your parents when you're 13 or 14 I had when I was 20."

Lyn

Both Jean and Josh speak about the loss of "self" in their personal story line and May talks about the loss of a trusting and spontaneous self:

"Abuse is obviously wrong for lots and lots of different reasons but I think one of the things for me, about it, is it's like a kind of theft; a spiritual theft and drawing myself was a way of bringing my self back."

Jean

"I see him as a sad little man who stole my identity for many years and I've got my own identity now, I'm Josh, I know what my worth is. I know what I'm good at, I know the people who love me, I know the people I love and I can actually feel those emotions now, I'm not stunted."

Josh

"More than all of this, I hate what it has taken away from me. I would love to feel proud of something I have done and feel that it is, also, good enough. I would love to feel that sex is a wonderful, important thing that people share instead of thinking 'please don't let anything go wrong.' I wonder what it would be like to be around people and trust them. I wonder what it would be like to have a one-night stand. I know some people might think this disgusting but everyone should be able to choose what they do with their body. I would love to feel the way that others do about their birthday. Look at clothes and buy them because they are nice rather than not buying them because I know I would be self-conscious and worry someone would use the way I was dressed as an excuse."

May

Addressing the losses described has been achieved, or is being achieved, by a number of means including therapeutic work undertaken in a formalised therapeutic setting or personal therapeutic work happening outside this type of context. For some participants, their involvement in the research process has been another avenue for facilitating the creation of a different type of narrative and, by doing so, has also validated the self.

I begin with the words of Lyn who talks about the use of transference and counter-transference in the psychotherapeutic encounter to re-work aspects of adolescence:

“So therapy has been helpful, immensely helpful, but not in the way that I thought. I thought ‘okay, I’ll talk about it and having talked about it I’ll feel better and then I’ll get on with my life.’ A lot of it, in that situation, is a kind of re-enactment, seeing my self behaving like an adolescent in the therapists room and not being quite able to believe that I’m doing this, and yet still doing it, and being aware. Talking to him about the boundaries and being very clear about those, and why they are being held, meant that it had become possible to talk about my insecurities about boundaries. Because I think when you’ve been in a relationship with somebody older, who ought to know how to manage that, and doesn’t know how to do it, you feel that you have to do it, the responsibility lies with you and that means that you dare not even explore the thought of what might happen.”

Lyn

Equally as important, some participants also spoke about therapeutic work happening in a less formalised manner and here Josh describes his attempts to reclaim something of childhood:

“And as daft as it sounds, because when I was a kid I didn’t have many toys, now I buy myself toys, and so on my shelf in the bedroom I’ve got my Peter rabbit, I’ve got my rubber ducks, and I think that’s really nice. My wife actually bought me the Peter rabbit many, many years ago, at the stage when I was still getting through it. I’d give him a cuddle, I’d sometimes take him to bed and that was fine. He’s always on my shelf now; I don’t need to do that anymore. A few years ago I saw these three yellow rubber ducks and I wanted them, and I thought ‘well I want them, so have them.’ So I don’t have a bath that often because I’m often in the shower because it’s quicker, but occasionally I’ll have one and I’ll take my ducks with me, and it’s okay to do that because we never had that when I was a child. I didn’t have any toys, I didn’t have any love, I couldn’t be a kid, so now...”

Josh

“The other week I was down in a little town a few miles from here, and I needed a new wallet and I bought a new wallet, but while I was in the shop I saw this pig and it was a blue pig, a money box with pink spots on it, so I thought ‘I want that,’ so I bought it, and now I stick my coins in it. And it’s allowing your self to have that time back almost, and whilst I’m never going to have the time back, I think ‘well I don’t

care what people think now, if they think I'm daft, if they don't like me, well that's not my problem, that's theirs.' "

Josh

Jean and Josh speak about "grounding the self" and alternative methods of putting themselves (both as adult and child) back in the picture/narrative.

"I work with mirrors a lot and when I find myself gone and I'm struggling I can bring myself back by looking at the mirror and focusing on my face and my features. So I started doing self-portraits and I still am continuing; making art is a very important part of the process for me."

Jean

"I found that picture recently (indicating the picture on the wall), it's the only picture that I've got of me at about eight, and I look at that and I think 'well, that kid there, he's smiling, he looks quite a happy little chap, but he was going through hell at that particular time.' So I put the picture up because he's me and I'm him, and we're both connected."

Josh

Similarly, participant's involvement in the research process performs a comparable function:

"Bearing witness is really important and being involved in research like this is a way of witnessing what happened. One of the things I have is this extreme 'manicness' going on, it's very hard to explain to somebody else but I was experiencing it a lot when I first cracked up and one of the ways of trying to handle it would be to try and occupy myself. So I had a number patience game that I would do, and I had the TV on, and I'd have music on, and I was obviously not focusing on any one of them in the way that you would if you were just doing one of those things, but I was in fact doing all three things because I needed to completely occupy my mind. One of the things I remember that particular time was that the Oscars were on and it was at the time when Schindler's List won a prize. One of the producers came up to speak, he was a survivor of the camps and he said, 'I remember at the camp looking into the eyes of a dying man and he said to me witness this, witness this,' and the producer said, 'I feel that I have been able to do that at long last with this film.' I was just in pieces; it spoke to me very much in that moment, in that I have to witness my experience."

Jean

"Having it (the narrative) all in one place is useful because when you have counselling you deal with separate bits at a time. I know people say that (by breaking it down) you can see how that relates to that, but I don't think that it sinks in the same as having it in front of you."

May

In addition to the reconstructive process, detailed in the previous section, recovery from an experience such as child sexual abuse, involves the acknowledgement and mourning for the losses incurred by the experience. This recognition is referred to by Herman (1992) as the second stage of the recovery process and is signified, she believes, by its ongoing quality. The acknowledgement of loss has, for some participants in this study, precipitated a search for methods of incorporating the loss, and its significance, into the plot structure of the narrative (Neimeyer et al., 2002). As a consequence, it has enabled the "weaving together of disparate fractions of identity" (Neimeyer and Stewart, 1996) and the production of a more reasoned life history account.

The losses incurred by child sexual abuse are both invisible and generally unrecognised as episodes requiring grieving. Hopkins and Thompson (1984) are perhaps two of the first academic writers to make the link between rape/sexual assault and bereavement, and apply the widely recognised stages of loss and mourning, described by Kubler-Ross (1969), to the issue of sexual abuse. Notwithstanding individual variables, Hopkins and Thompson identify three particular losses identified by survivors of child sexual abuse. These losses include the loss of trust in others, an issue prevalent in May's quote and also referred to in the last chapter by both Josh and May (page 135). They also include the loss of freedom and an ability to do things such as accept lifts home from colleagues, and buy clothes and make-up without having to be concerned about any potential negative repercussion, a point also made by May. Additionally, the authors identified the loss of what they referred to as ego identity, and I refer to as "self." Here, the authors describe this loss in terms of loss of security, consistency, certainty, rootedness etc. Jean and Josh talk about this loss in terms of "spiritual loss" or "loss of identity."

Similarly, Bourdon and Cook (1993) researched the issue of loss with fifty-three female adult survivors of sexual abuse and fifty-eight mixed gendered therapists using questionnaire methodology and background information sheets. They identified five loss categories which comprised: developmental, sexuality, relationship, self-esteem and general, but did not deconstruct these categories further. For both survivors and therapists, the most significant losses identified were a loss of trust (also identified by Hopkins and Thompson 1984) and the loss of self-love, an issue referred to by Jean when discussing her personal recovery process in the previous chapter (page 118). Both trust and self-love were seen by both parties to be integral to the ability to form and maintain positive adult relationships. The age at which the original abuse occurred was also felt to be very significant in Bourdon and Cook's research; they concluded that the earlier its occurrence in childhood, the more perceived losses were reported later by survivors.

As described in the previous chapter (page 153) child sexual abuse occurring early in life can interfere with the foundational development process and influence such issues as attachment and separation (Clarke, 1993). In terms of the developmental losses identified by participants in this study, Lyn described the lack of familial circumstances that could facilitate an ability to safely engage in the typical boundary testing behaviour that signifies adolescence and which is part of the individuation process. For Josh, the loss identified was the loss of the socially constructed "idealised childhood" (Scott et al., 1998) that is characterised by "child-like concerns" and, within that ideal, the loss of a normal sexual developmental pathway, an issue discussed by both Thomas and Josh.

In relation to this latter point, and to elaborate further, research indicates that for non-sexually abused 2-6 year olds their actual sexual knowledge is very limited. They are aware of genital differences and the non-sexual function of genitals, but, according to Brilleslijper et al. (2000), are generally not concerned with things that do not occur in their own lives. Any sexual exploration that does present usually happens between peers, often with older child friends, and in the context of play where children "play at marriage" or

“play at doctors” (Ryan, 2000). For sexually abused children the situation is very different and they are exposed to experiences that they are developmentally ill-equipped to deal with and which can then result in “sexual re-experiencing behaviours” such as sexualised play, public or compulsive masturbation etc. (Deblinger et al., 1989).

Again, therapy is one avenue for acknowledging and mourning the losses experienced in childhood. Here, the establishment of a consistent and nurturing therapeutic relationship can provide the potential for analysis of early attachments. It also provides an alternative and re-constitutive “self-object mirroring experience,” which provides containing features and a validation of the self (Neuman Kulp, 1991). Sometimes the mechanics of the therapeutic encounter, that are responsible for precipitating personal growth, involve transference and counter-transference dynamics. As described in Chapter One, page 14, these terms derive their meaning from psychoanalytic theory (Laplanche and Pontalis, 1988) and refer to processes whereby feelings from childhood are stimulated for the individual who then transfers emotions associated with primary objects in their life onto the therapist, expecting a particular response (Etherington, 2000). The emotions stimulated in the therapist (counter-transference) are used as an indicator of the individual’s past experiences and also as interpretive material that can be shared with the individual. In that sense the therapeutic alliance reveals the past and considers alternative and more productive ways of relating.

The “acting-out” behaviour, described by Lyn, which is typical of therapy generally operates outside the conscious awareness of the client and is symptomatic of the individual’s attempt to communicate painful emotions, which defy verbalisation. Ganzarin and Buchele (1987) contend that acting-out behaviours are “coded messages from the patient’s unconscious.” They believe that it often takes the client some time to understand the message embodied within the behaviour, work through its meaning, and finally become free from the repetition which typically occurs within their interpersonal relationships. Although Lyn describes her experiences of therapy in very positive terms, it is, perhaps, worth pointing out here that some disabled

people's experiences of therapy, in general, are far from positive. Corker (2003) argues that for the disabled individual it is possible for the socially and professionally entrenched value systems, associated with the medical model of disability, to impinge on the therapeutic relationship to negative affect. This is particularly possible, she contends, in psychoanalytic practice where the "root metaphors" and oppositional constructs (normal/abnormal, sane/insane etc.) have the potential to influence the theorisation of impairment and the causality of current difficulty. Swain et al (2003) also raise this issue but in relation to the counselling setting, arguing that there is a danger that individualising approaches can preclude the social context of disability and the very real obstacles that disabled people face in relation to their inclusion in society. Corker (2003) believes that this is an issue that can be confronted by an increase in the practitioner reflexivity and professional training in disability issues.

Of course, as indicated by participants in this study, there are other avenues available for mourning the losses aside from therapy/counselling, which also enable the individual to place the "self" back in the narrative. Josh, for example, although recognising that what was stolen in childhood is irreplaceable, has referred to the symbolic re-claiming of childhood. This has been reflected in his purchase of toys, which have been used in difficult times as a source of comfort, and the relocation of a childhood photograph in a prime position within his home, so indicating the retrieval and ownership of his childhood identity. Additionally, Jean's use of mirrors and her artwork are examples of self-affirming methods and ways of re-establishing the self within the personal narrative. Writing is also a well-recognised therapeutic tool used in the recovery process of survivors (Green Lister, 2002), which can serve a variety of purposes. Although not acknowledged within this section, but referred to in the methodology chapter, both Thomas and Jean have used poetry as part of their recovery process (**Appendix G**) and as a means of emphasising their presence in the abuse experience. Thomas has also produced an extended and detailed autobiographical account of his earlier years. The power of writing, according to Etherington (2000), lies both in its

cathartic effect, it's potential to deepen understanding and its ability to put "the indescribable into words."

Etherington (2000), by drawing on the work of Frank (1995), posits the existence of three types of written narrative: the restitution narrative, the chaos narrative and the quest narrative. The restitution narrative, according to Etherington, has as its central theme the "return to how things were before the event." The chaos narrative reflects the suspension of the individual in their current dilemma (an issue which will be picked up on in the next section of this chapter). The quest narrative can contain a sense of reflection and a motivation to bring about social change by exposing truths and informing others. Clearly, many research participants, mine included, undertake the co-construction of a narrative within the context of the research process with the intention of producing a "quest narrative." This quest narrative, according to Robson (2001), is often a testimony to an experience that society would prefer to ignore and has both a personal healing effect and political function. As Jean describes, it is a form of "bearing witness" to a societal atrocity but also acts as documented confirmation of the experience and validation of the self, an issue which may also have some validity for May.

Similarly, Swatton and O'Callaghan (1999) offer other dimensions to the function of the narrative produced within the research context. Here the issue of mirroring is raised, where the narrative is described as a mirror, which can be used to "reflect upon the self and offer insights and possibilities in the future healing process." Swatton and O'Callaghan also employ the concept of the evoked companion (Stern, 1985), feeling that the research narrative can provide a prototype, which can "inform and evaluate subsequent life experiences." Again, these functions may have some significance for May and Jean.

In concluding this section, it is worth returning to the writings of Herman (1992) who emphasises the importance of the mourning process. She believes that survivors often try to resist the mourning process, for fear of becoming locked into a never-ending cycle of grief and instead may be

tempted to become involved in “fantasies of revenge or forgiveness.” She argues that, despite the work involved in the mourning process, eventually, over time, the trauma narrative will no longer occupy such a prime position in the survivor’s life. I feel it safe to say that participants in this study are at different stages in this mourning process.

b) Narrative chaos: “there was a constant feeling of not being able to not feel it anymore.”

Within this section, and as indicated earlier, I will deal with the process of narrative chaos, where in later life, and when dissociative processes became less vital for survival, the individual’s circumstances dictated a necessity to re-engage with, and make sense of, the abuse experience. The consequence of this process resulted in narrative chaos, or what Frank (1995) describes as narrative wreckage, whereby incoming information had a destabilising impact on the self and further suspended an ability to narrate the self in coherent terms.

The process of being forced to engage with the abuse narrative has been a significant feature of most participant’s stories, triggered by a number of factors, variable in their nature, and sometimes accompanied by detrimental consequences. For two participants, who had repressed or forgot the sexual abuse experience when very young, and who had no conscious awareness of that experience in early adulthood, they retrieved the memory later in life and, as a consequence, gained a retrospective meaning-making function to their personal narrative. For two other participants, who had continuous recall of abuse memories, their involvement with small children, either as a mother or as a baby-sitter, created a situation whereby their dissociative defences became ineffective and raw emotion relating to their violation became exposed for the first time. For one participant, a sibling’s partial disclosure forced the individual to divulge his own abuse to his partner, with the following recovery of further abuse memories that, up until that point, had not been present.

Most of these participants, at the time, had a safe enough environment to risk the further exploration of the abuse narrative. For one participant, at the time of writing, the presence of intrusive images and sensations continue, so signifying their unrelenting involvement in the process of working through the abuse memories, and their continuing state of narrative chaos. As with many of the participants, there is acknowledgement, by two particular individuals, that there are gaps in their narrative, with one person contending that further recovery may have the potential to bring about additional disruption in their life. I will begin, however, with the words of Lizzie who describes the recovery of repressed memory in counselling, following an incident of physical assault whilst living in India:

"In terms of recovering the memory of sexual abuse, I went back to live in India for a couple of years in the mid 1980s and whilst I was there I was attacked during a robbery at the place where I was living. And it was when I got back and I started co-counselling about the attack. It just... I can't explain it except that I think that I knew that one of the things that my abuser did in hospital... because he didn't only sexually abuse me, most of them don't do they? I think one of the things he used to do was hit kids on the head, because if you do that you don't leave a mark, the mark is hidden by the hair, so I think he hit me on the head. There are other reasons that I think that, but in this attack I was hit on the head with something a bit like a scimitar: a curved blade that is either used for cutting crops or attacking people. So it was counselling on that and suddenly I just knew, I just knew I'd been abused in hospital. You've got to take into account by that time I was 37 and I had been already co-counselling for 15 years"

Lizzie

"But what it means is that I had done quite a lot of preparatory work to make it possible that when the trigger was sufficiently similar it was safe for the memory to come back. I could handle it by then."

Lizzie

"Through counselling, what emerged over the years were snapshots, which I'm sure other women would describe i.e. that if the abuse happened when you are very young, in fact preverbal, you can't describe it, no that's not true, you can end up describing it but your memory is not words, your memory is photographs or body memories frozen in time. So gradually I would uncover little bits and little bits more and little bits more."

Lizzie

Lizzie describes the relief gained by retrieving the memory and being able to produce a more coherent narrative:

“Each time I put together another piece of the jigsaw it was a relief, but I don’t really feel like I have completed the jigsaw actually. I probably haven’t but each time another piece slotted in it was a huge relief because I knew life had to be better having slotted that in, than without it.

Lizzie

For Jean there had been a number of triggers that precipitated the recovery of the repressed memory including: her mother deciding to share what she knew about Jean’s first period of hospitalisation, her daughter reaching the age when Jean was abused, the presence of a supportive partner and network of supportive friends, and Jean deciding to stop smoking cannabis following an illness episode:

“Something happened when I was about twenty six, when I went to visit my parents, my mum had decided that it was time to tell me and she sat me down for the first time and she told me the whole story of what happened in hospital, in detail, from her point of view. The information that she had was shocking and upsetting even though it didn’t include all the information I later retrieved as repressed memory.”

Jean

“When my daughter was around the age when the abuse started to happen to me in the hospital, around eighteen months, things started to really go down hill for me and I was really struggling. I don’t think that was a coincidence. I was still smoking and really wanted to stop. I got myself therapy. I’d got that far, I’d got a therapist set up and I’d had an initial meeting and a first session with her. Then it hit Christmas time and I got very ill.”

Jean

“And then, when I was just beginning to come out of that (chicken pox) with the help of antibiotics, I decided that I was just going to stop smoking. Looking back on it I think ‘well that was interesting that I did that,’ I just completely stopped and within five days I was just completely gone; completely in an altered state.”

Jean

Here Jean talks about the process of memory recovery and the form of that the memory took:

"I'd shaved my head and I wasn't eating at all. I think that the time was just right really for it to all erupt, and suddenly I was in this world of feelings and sensations and these bodily experiences, it was very intense. I had some friends who knew enough about the process of repressed memory to be able to help me. So the second therapy session that I went to, I was led to the door in this very frail state. Luckily my therapist was great and handled it really well."

Jean

"So I was in this altered state for a while. I was weak, I was doing that kind of process that people do, you know, trying to understand the physical sensations and the dreams. I'd been having dreams for a long time that I didn't understand, so it was that process of putting it all together."

Jean

"There is a difference between repressed memory and recall memory, and some of what happened I have in recall memory and a lot of it is repressed memory, and to me the nature of the memories is quite different. There is a lot of evidence to suggest that we process the memories in different ways. So for repressed memory, as well as the visual images of tiles and things, there were also smells and the feel of things, like cold metal. I got cold metal, she had a cross on, a big flat cross, and there were times when the nun was abusing me where it was banging into my face and I got that sensation of a cold flat metal thing against my face. And sounds, but not words or phrases in the same way as later on. I think the recall memory and the repressed memory is different, the repressed memory is always a lot more 'trippy' and like an altered state, which would make sense. A lot of my recall memory is quite visual too."

Jean

Additionally, she comments on the role that therapy played in the recovery process:

"The therapy that I was doing was called 'process orientated psychology,' which is very interesting because it is very client focussed, it's all about the process. So the therapist really worked with me and what I was doing, I wasn't getting the memories in therapy, it was mostly happening at other times and therapy was helping me with the tools to understand what was happening and to

start to put together the picture of what had happened in the past and how to deal with it now.”

Jean

In these next quotes Jean talks about the costs and benefits, for her, of recovering and actively engaging with the recovered material:

“But there’s a costs for that, and I think that for some people those costs are too great. Overwhelming, is an incredible understatement, nobody dies from feelings but you can die from the consequences of feelings. I did get very close to suicide when things were very bad in that first year, when I was feeling those intense feelings of fear and pain and self hate: the hate that the nun put on me, and the hate of those medics who were able to objectify a person to the extent that they can justify murder.”

Jean

“My relationship did not survive unfortunately, which is the case for a lot of people that go into crisis around child abuse. It is very rare that the relationship will survive it. It was very hard for my partner because she wasn’t skilled, or knowledgeable, or confident with emotional issues.”

Jean

“The process of uncovering the repressed memory is a process of survival in itself. I think that many people do carry on their lives without recovering the memory and that’s maybe okay for those people. But I realised that I needed to live my life, I wanted to have feelings and I didn’t want to live this dispassionate, disconnected kind of life. That is happening for me, and again it’s slow, but I’m getting there and I do cry now, I am able to do it, and I am much more in touch with my feelings.”

Jean

Lynn and Chloe speak about how, at some point, the anaesthetising effect of dissociation began to wear off for them, and difficult emotions began to surface, creating a breakdown in their mental health (suicidal ideation in Lynn’s case and psychosis in Chloe’s) and an accompanying narrative turmoil. In both instances the trigger appears to be the exposure to young children and below both women elaborate further on this point:

"A good part of it was that my boss, whom I'm a good friend with, has 2 daughters, and he's very affectionate to them. I'm quite sure that there is nothing sinister behind that but I couldn't read it right. When I saw it I didn't know what was happening. I'd get very upset; I'd know that I was behaving irrationally. I'd have to make an excuse to leave the room. There was an occasion when I babysat for them, at that time they were about 5 and 8, and the 5 year old came to say good night to him and sat on his lap, she sort of squirmed around and her night dress rode up and she wasn't wearing any knickers, and he wasn't at all embarrassed about this. He had his hands around her chest and she was sort of leaning backwards and tickling his chin and she was obviously completely relaxed and happy with him in a way that I never was with mine, and I just couldn't bear it, I wanted to pick her up and take her away or just abandon her to him. I just didn't want to watch it, what I thought was going to happen, even although rationally I knew it wasn't going to happen. His wife was around too, and the other girl was there, and he would have never done it in front of me. But then part of me felt 'well my dad did it in front of other people.' "

Lyn

"Iqra started to become a toddler, become a little person. And I think it was something to do with her just getting just that bit older and becoming a little person. And again at that age they start....already you start to see early sexual behaviours that I didn't want to acknowledge were there. But they do start having their early sexual behaviours that again as a responsible adult you just encourage them... 'If you want to do that, do it when you're in the bath on your own.' And that's the sort of stuff that I think was going on with me, those sorts of things. I think there is probably an age connection, she was probably a similar age to when maybe my memories are coming from: the one's where I don't really know what happened. So I'm looking at her and I'm also thinking she's just brilliant and someone's going to come and want her because look at her, who wouldn't, I mean she's fantastic, she's the best kid in the world. And again because she's disabled, so I know she's more vulnerable and I think that's what started going on and I didn't want to leave her with people."

Chloe

As a consequence of these triggered emotions, Lyn describes the process of getting to the point of needing to seek help:

"So it got to the stage where there were too many things that I couldn't think about. I was spending my entire life lurching from topic to topic because everything became too dangerous, everything

reminded me. There seemed to be constant references in the newspapers, I couldn't look at a man with a child in the street."

Lyn

"There was a constant feeling of not being able to not feel it anymore. I was apparently doing all right, I was still functioning at work, nobody was saying to me 'god what's wrong with you,' so clearly I was still hacking it, and yet inside I felt awful. At its peak I was going 15 minute stretches of not thinking about killing myself. I was thinking 'if I can get through the next 15 minutes without thinking about it, and then the next one,' and this was all without really consciously relating it to anything that had gone previously, I just felt dreadful."

Lyn

"What once had been deadness was no longer deadness, the anaesthesia was wearing off and there was a kind of despair that it was wearing off, and I had no idea how bad it would get. I'd been thinking 'I can't live like this, but supposing I woke up tomorrow and it actually felt twice as bad.' It was like living with a physical pain and trying to gauge at what point you take the Asprin or something stronger. But there didn't seem to be anything I could take, and all the strategies that I had had for coping with it were no longer working and I didn't have any others."

Lyn

Thomas's acknowledgement of his abuse followed his sister's disclosure and also led to a emotional breakdown which was accompanied by flashbacks and the retrieval of repressed memories from early childhood:

"The flashbacks started about six months after it all came out. I started to have really bad night terrors and I wet the bed a few times. I'd wake up as though I couldn't breath, you know, like a panic attack. Obviously I'd be having it in my sleep and I'd wake up and I couldn't breathe."

Thomas

"During the day there were strange little things like: we'd go out somewhere and I'd see something and it would just be like someone playing a videotape backwards, I'd feel scrambling in my head, and I'd try and adjust my eyes and next minute I'd be either back in my living room at 39 West View, or in the bathroom. And my step-dad would be there and I could smell his aftershave, his body odour, and

things like that, and I'd just feel like I was going to black out. When this happened we would just have to go home."

Thomas

"I think that that initial disclosure to Sharon, and her acceptance and support provided a sense of safety that allowed the memories to start flooding back. Whilst I always knew I had been abused, the early memories were out of reach. Bit by bit the pieces of the jigsaw started fitting into place. It was like...I went walking one day in Pleasley and came across a dry-stone wall. The image started to play on my mind, and gradually over time, I started to recover the memory of the camping trip in Matlock, which hadn't been there up until that point."

Thomas

In May's situation the narrative disorganisation continues with intrusive thoughts and memories frequently breaking through into consciousness creating a situation where the abuse experience still feels very much part of the present:

"I'm not sure if this happens because there is so much to cope with. It must be very difficult having to deal with someone who keeps 'dropping out' as I call it, something, which happens because of my abuse. I cope by just blanking it out, and then coming back when it is over. It has the reverse effect these days, anything can make me 'drop out,' a word, a touch, a smell, but rather than taking me away from the way I feel, I seem to get locked into a re-run of something that happened. It must be frightening for people around me because I'm just not there; it is like being unconscious. Flash backs cause a similar thing; it's like being there, and it all happening again. Flash backs can cause me to be very violent, it is like this feeling of anger or hatred of my self comes over me and I just have to get it out. I usually end up trashing a room or self-harming. When I come back to myself I feel horrible because I feel like they have controlled me again. I also cannot believe what I have done sometimes; I am scared that one day I will hurt someone. I also feel dirty and disgusting, which means I have to get in the shower for ages. I go from really hot water or stone cold, without knowing, because I am obsessed with washing. I find that things that are on TV, or other things that I can't quite figure out, can cause flash backs or mood swings."

May

These last two quotes from Josh and Chloe acknowledge the incomplete nature of their narrative, with Chloe recognising that further retrieval also has the potential to create narrative chaos:

“These memories have always been with me but there’s a lot more I don’t remember.”

Josh

“I know that I’ve got memories to come, that haven’t come yet, and I want them to, I want to have them. Not that I particularly wish to remember it, you know, it’s not like it’s enjoyable, but you want to know what’s happened. Because people do get flash backs, they get them suddenly often as well.”

Chloe

Participants in this study demonstrated varying degrees of repression of the abuse memory ranging from complete amnesia, as detailed by Jean and Lizzie, to partial and continuous recall, as described by Lyn, Chloe, May, Thomas and Josh. This finding is consistent with the research of others (Fivush and Edwards, 2004) who have conceptualised the process of remembering and forgetting as a continuum of experience. Research with both clinical and non-clinical samples illustrate that delayed recall of sexual trauma in childhood is not an uncommon phenomenon. Elliott and Briere (1995) found, in their non-clinical sample, that 42% of participants reported some level of amnesia, whilst 20% described a period in their life when they were completely amnesic for their sexual abuse. Andrews et al. (2000), by comparison, whose research involved the narratives of therapists of child sexual abuse survivors, reported total amnesia in over half of their clinical sample. Some of these individuals described prior unconscious clues (as referred to by Lizzie in the previous chapter, page 148) such as distressing dreams etc. Or, in the same way that Jean recounts, people in the individuals network sharing knowledge relevant to their abuse, but with the individual concerned having no conscious memory of it. In Chu et al.’s clinical sample (1999), where a significant number of participants also reported partial or total amnesia, many were able to produce corroborative support for their experience in the form of professional case notes (89%).

Researchers such as Briere and Conte (1993) have found that amnesia is associated with violent abuse, multiple perpetrators, abuse accompanying threats concerning disclosure, early onset of abuse and a longer duration. Chu et al. (1999) also confirm this strong relationship between early onset and greater levels of amnesia, as in Lizzie and Jean's case, with Williams (1995) finding, in her study with women whose abuse was documented by statutory agencies, that the age of onset of abuse, and a poor level of support gained from a parent after the abuse incident, increased the likelihood that the abuse would be forgotten. Williams (1995) makes the relational link between age of onset and cognitive developmental features in the child. Others' research, by contrast, refutes most of the connections detailed above (Elliott and Briere, 1995).

For the participants in Andrews et al.'s study (2000), the triggers for abuse recall were variable, and included: some form of physical contact or danger to the client (13%), as described in Lizzie's situation, a change in medication or substance use (4%), as described by Jean, or the disclosure of another (4%), as detailed by Thomas. Similar to research that demonstrates the impact of pregnancy on the recovery of abuse memories (Jacobs, 1992), Andrews et al. found that for 17% of their sample the trigger involved their children, either in terms of particular events, or their child reaching the same age and stage of development that they were when they were sexually abused. This issue was also relevant for Jean.

For both Chloe and Lyn, who had partial or continuous recall memory, their involvement with children, both their own and others, triggered the recovery of a painful emotional state that had previously been repressed by dissociation, and which also created internal instability (Elliott and Briere, 1995) and consequent narrative chaos. Of particular significance for Chloe was the fact that, like herself, her daughter also had an impairment, which potentially increased her vulnerability, in Chloe's eyes. The recovery of memories of child sexual abuse in therapy has been the subject of continued controversial academic debate, which will be covered in more detail in the next section, but for the participants in the study conducted by Andrews et al. (2000), therapy

acted as a trigger for memory recovery in 37% of the sample. For 22% of this 37% sample, therapy provided the exploratory questioning mechanisms and ensuing discussion, which facilitated memory recall. In only 15% of these 37%, recall resulted from the use of a therapeutic technique, such as hypnosis or guided imagery. For Jean, the role that therapy played in relation to the recovery of her repressed memory was seen to fit neither of these categories.

Research also indicates that individuals who have delayed recall, from a prior state of dissociative amnesia (see Chapter One, page 14), show an increased demonstration of symptomatology in the early years of memory recovery. This symptomatology includes such things as depression, anxiety and flashback that can take the form of intrusive images or sensations (Elliot and Briere, 1995; Evans and Maines, 1995; Norman, 2000), this latter point being clearly visible in Jean and May's narrative episode. Similar to some of Thomas's recollections, participants in Andrews et al.'s study (2000) described these flashbacks experiences as either full or partial re-living experiences, with the majority of the participants (60%) experiencing "all or part of the event in the present, with bodily or other vivid sensations and intense affect." In fact Evans and Maines (1995) describe this state as the individual being temporarily locked into the past, an issue powerfully detailed by May. As in May's case, these re-living experiences can also be accompanied by distressing emotion such as guilt and self-disgust (Andrews et al., 2000). Elliot and Briere (1995), who, in their study, used a large-scale, computer generated, non-clinical sample, propose that these symptoms decrease with time but that this increased symptomatology connected with new access to repressed material in the early stages of the recovery process, could reflect, for that individual, a "resurgence of the affects associated with the original trauma." These authors contend that, although distressing at the time, exposure to sensory information, in the form of flashbacks, could have some therapeutic benefit by gradually desensitising the individual to components of the recovered memory.

Andrews et al. (2000) found that the majority of the memory recalled in their study occurred in the form of episodes, rather than autobiographical facts, and

that initially the memories were fragmented (2000). This finding is consistent with the writings of van der Kolk and Fisler (1995), who draw on the work of van der Kolk and van der Hart (1991) and who contend that overwhelming trauma information is encoded in the brain differently to other non-traumatic life events. They assert that this trauma material is predominantly organised in the memory on a “sensori-motor and affective level.” Accordingly, it appears in later recall in the form of sensory fragments of the initial event, which include such things as visual imagery, auditory and olfactory stimulation, bodily sensation, and overwhelming emotion, all of which Jean, Lizzie, Tomas and May describe. In some individuals this memory is entirely perceptual, with no verbal component, a fact that is corroborated by neuro-imaging studies (van der Kolk and Fisler, 1995). This issue is raised in a quote of Lizzie’s and could particularly apply to abuse events experienced by pre-verbal children who do not hold memory in verbal representation, and who process events in a particular part of the brain structure, otherwise referred to as the amygdala (Courtois, 1999).

However, as indicated by Andrews et al. (2000), not all abuse recall takes the form of fragmented episodes and some memories are recovered in a more complete autobiographical format, with no re-living experience, which appears to be the case for most of Lyn’s memories. This occurrence gives support for the more physiologically orientated models, which advocate the existence of “dual representation theory” described by academics such as Brewin et al (1996). Brewin and Andrews (1998) argue for more than one level of representation of the trauma and believe that separate processing pathways potentially give way to both autobiographical recall and sensory recall, as in Thomas’s case. Although speculative in nature, other researchers argue that there are, in fact, three pathways responsible for the processing and retrieval of trauma memory. Two of these include the sub-cortical pathway and the cortex, both of which transfer messages to the amygdala. Both are sensory specific, with the latter having more conscious representation and the ability to process some trauma related information. In addition the hippocampus (the third pathway), which is deemed sensory-independent and involved with long-term and autobiographical memory, is argued to be significantly impaired by

extreme trauma such as child sexual abuse, so interfering with its capacity to integrate these range of representations (Sivers et al., 2002).

Whilst many writers make no distinction between total amnesia and dissociation, as mechanisms for forgetting trauma, seeing them both as distortions in the memory (Erdelyi 1990). Others, such as Brewin and Andrew (1998), problematise this duality and identify them as different and distinct types of processes. They believe that dissociative processes, similar to the ones embodied in the quotes of Lyn, although accompanied by amnesia are essentially “alterations to the consciousness rather than forgetting” and that neither concept can adequately account for individual experience. Similarly, Epstein and Bottoms (2002), in their study of female college students, make a distinction between amnesia and active cognitive avoidance, which is how some people may categorise dissociation. Within this section of the chapter I have certainly combined the two phenomena and believe, in terms of the concept of narrative chaos and the recollections that are involved, they both produce a similar effect.

From a narrative perspective, recovered memory, and the breakdown of emotional defences that have previously protected that individual, can create intense anxiety with the result that the abuse memory cannot be transferred into “neutral narrative” (Uehara et al., 2001). In fact, it creates what Frank (1995) refers to as narrative chaos or narrative wreckage, where the regular functions of an individual’s narrative, such as continuity and coherence, meaning making and self-evaluation, become de-stabilised (Tuval-Mashiach et al., 2004). Frank (1995), who writes principally in relation to the illness narrative, contends that chaos narratives signify a suspension of the individual within a crisis, where an ability to verbalise and reflect is denied. People operating in narrative chaos, according to Frank, experience a lack of control and an inability to order their narrative. Any attempt by outside individuals to “push the person through crisis compounds the chaos” and typically, as Jean recounts, relationships surrounding the chaos narrative may break down. May’s latter quote is highly illustrative of what Frank refers to as “chaos embodied,” where predictability is illusive and there is a seemingly never-

ending quality to the individual's level of pain. Here, as May describes, the body is seen to be dangerous, self-injuring and potentially violent towards others, so creating, what Frank asserts is, both a need for dissociation and ultimately a lack of self-recognition.

As previously indicated, and as present within Thomas's quote, healing stems from the ability of others to hear the individual's pain and perhaps, on a secondary level, at least, experience their fear and loss (Uehara et al., 2001). Verbalisation of the trauma and the processing of the memories, as described by Jean, is a painful exercise, which some writers question the validity of by arguing that defences such as forgetting (and dissociation) may be more preferable than exposing the trauma (Farrants, 1998). The advantages are also specified by Jean and Lizzie and include both an ability to live an emotionally integrated life and being able to produce a coherent narrative account of the self, which is structured, orientated in time, demonstrative of a degree of reflection and evaluation, and providing a sense of personal identity (Baeger and McAdams, 1999). Similarly for individuals such as Chloe and Josh, who know there are gaps in their narrative, the eventual retrieval of this information, despite causing more chaos, may provide the same function in terms of narrative coherence. Even when recall material is entirely perceptual (as in Jean and Lizzie's situation) research, including this work, indicates, that over time it is possible for that individual to construct an integrated narrative account.

By way of concluding this section, and on a political and sociological level, Uehara et al (2001) contends that the chaos narrative, in its telling, epitomises how the abuse/atrocities narrative "crosses over from the public space to the traumatised inner space" and then "crosses back" in the survivor's attempts to bear witness to the experience in its later re-telling. I would also argue that, in addition it "crosses back" yet again, a third time, so bringing about narrative coherence at a personal level.

c) Narrative reliability: “I’ve been brought up as the one who makes it dramatic”

Within this section I will discuss the participant’s views on the historical truth embedded within their emergent sexual abuse narrative, its believability for others and the rumination they are prone to themselves. For the two participants who had been abused in early childhood, and who had then become amnesic for these memories, although very clear about the validity of the recovered information, they experienced variable reactions from others about these recollections. In Jean’s case, she predicts that she would receive a similar degree of scepticism should she inform outside agencies. Other participants spoke about the perceived plausibility of their life story, in general, or discussed family dynamics and impairment related issues that have had the potential to undermine it. I start with a quote from Lizzie and Jean who talk about the problems for others of believing recovered memory from such a young age:

“So the main abuse happened between 14-18 months and one of my worries has always been that people would not believe me because I was so young and I’ve got nothing faintly resembling proof, but when I realised it, it made sense of so many things about me.”

Lizzie

“Repressed memory is hard to explain to other people and I know it sounds very odd ‘these awful things happened and you forgot and now you’ve suddenly remembered!’ It sounds ridiculous.”

Jean

“I am doubtful I will be believed particularly around the euthanasia stuff. I know that people don’t want to believe that it happens, and also with me being so young when it happened; I know that the repressed memory is not valid in the same way as recall memory.”

Jean

In this next selection of quotes Lizzie and Jean talk about the reactions of their parents to their disclosure of recovered memory:

“It was difficult that it was my dad who was counselling me, (because I taught my dad co-counselling) at the moment that I first uncovered the abuse. And he found it very difficult to believe, which is extremely understandable. So that was unhelpful but not devastating because he didn’t rubbish it, he wouldn’t do that. But I knew he was wrong, you know, I knew he was wrong. It was such an absolute moment of knowing, it wasn’t a kind of maybe; it was an absolute moment of knowing.”

Lizzie

“My mum couldn’t cope with it really and of course she would never poo poo it, but I don’t think she really wanted to think about it. She really didn’t want to accept that it was probable rather than improbable. So she never stopped being very loving and very supportive of me, but I never took the issue to her. And also because I could see how awful it would be for a mother to discover at any point, even thirty odd years on, no wonder she wanted to say ‘no I don’t think so.’ “

Lizzie

“When I cracked up I decided to tell her and they came up, mum and my step-dad came up and stayed for a few days. She helped with some bits of information. I think she had been expecting me to crack up. I’ve not told her all of it, it’s difficult because she sometimes says things and does things that are very insensitive. I think that’s part of her process, she’s carrying a lot of trauma, she’s still very affected by it, and she doesn’t have all the information. I did talk to her specifically about the anal abuse; I haven’t yet talked to her about the water stuff or the ritualistic nature of the nun’s abusive behaviours. I did talk to them about the murder and, to be honest with you, I’m not quite sure whether they believe me or not. But I was quite clear with myself when I told them, that I didn’t need them to validate this in any way. I don’t need that because I know it happened. I’m a hundred percent sure about it. From the moment I had it I was just a hundred percent, and the detail of it has never faltered, I’ve never felt doubtful about it. I’ve had more doubts about the other stuff than I have about that.”

Jean

In the following two quotes Jean discusses her feelings about how the authorities, including the legal profession, would respond to the recovered material:

“Passing the information on to the authorities was never a feasible option because it was so long ago, and also because I know I’d be greeted with a lot of scepticism from people. I’ve always felt that it’s

pointless to go to the authorities with this, there's probably nothing they can do now."

Jean

"I've never had an expectation that I'm going to ever get any kind of legal justice with this....."

Jean

For Lyn, who had continuous recall of her sexual abuse experience, she describes the feared, and potentially rejecting, responses of others to her life history account:

"I discovered when I started telling people about this sort of life history that I found myself thinking this life story is beginning to look implausible because it's so awful. It took something like 2 or 3 years for me to risk telling somebody and wait for them to vomit on the floor or sort of send you out of the room, which is what I thought would happen because it was just so awful."

Lyn

Chloe describes her parent's dismissive attitude toward the validity of her discourse, in general, and how this has impacted upon her self-confidence and, perhaps, her sister's ability to stand by her own previous abuse allegations made against her father. Later Chloe talks about the impairment related difficulty that she encounters with memory that can, potentially lead to suggestibility:

"For half my life I've been told I'm a liar with a result that I don't even believe my own feelings three quarters of the time. I've been brought up as the one who makes it dramatic, I've been brought up as the one who doesn't really know what she's talking about....."

Chloe

"So my sister I know could quite happily sit there and say 'no I was lying' (about previous abuse allegations concerning her father) and even believe it, even if it had really happened. She would sit there and say it and think it was true, because they can actually make you think that things that you have actually done, that you were actually there when they happened, are not what they were. They can actually somehow do that to you, I don't know how, but you know a combination of fear and lies....."

Chloe

"I do take things literally and I don't remember things well afterwards. So if something happened to me, and someone kept telling me that something else had really happened, I would start to believe that, because that's what's in front of me now, that's real, and what happened before is a bit not really there."

Chloe

By contrast, Chloe describes her experience with the police when she made a statement regarding her extra-familial abuse. She later refers to her credibility as a witness in court:

".....but at the end of the day they've treated it as a complaint, as an incident, as a crime. They just believed me, and you think nobody is going to believe you. It's a thing that you have been told, it's so deep in your head: people won't believe you."

Chloe

"But I'd never be a good witness in court, if they found this little ring of people, I would never be a witness in court, I just don't remember enough things."

Chloe

In addition to the ambivalent and contradictory views held by society in relation to the issue of child sexual abuse (and as detailed in Chapter One, pages 18-19), the credibility of the child sexual abuse narrative, particularly those that involve recovered memory, is enmeshed within the recovered memory/false memory debate that surfaced in the US in the late 1980s/early 1990s (refer to Chapter One, page 14). This debate has a historical legacy, which dates back to the pressures placed upon Freud by his contemporaries in the early 1900s to retract, or at the very least moderate, his writings on child sexual abuse. This resulted, instead, in an emphasis on theories of childhood sexual fantasy associated with the oedipal stage of child development (Masson, 1984). The re-emergence of the recovered memory/false memory debate in more recent times has signified, for feminists, in particular, a societal "backlash" against the increased predominance of child sexual abuse in the media (Campbell, 1988) and the growing number of cases in the US, involving recovered memory, that were reaching litigation. It culminated, following a high profile case of recovered memory, in the establishment of the

False Memory Syndrome Foundation by the defendant in this particular case (Mollon, 1996). There then followed a subsequent and generalised distrust of therapists and social workers, so imbuing the subject of recovered memory with an air of suspicion, which has consequently influenced many survivor's concerns about the believability of their abuse narrative for others. This debate cannot fail to have impacted upon and underpinned, to some degree, the concerns relating to narrative plausibility/believability expressed by participants in this study. It will also, probably, have influenced the views of parents hearing their adult child's initial disclosure of child sexual abuse involving recovered material.

The emergence of the recovered memory/false memory debate was, correspondingly, accompanied by the writings of a number of key memory researchers, who have been seen, by some, to add some academic weight to the false memory argument (Loftus, 1993; Lindsey and Read, 1994). Neither of these writers appear to deny the existence of child sexual abuse nor, in the case of Lindsay and Read (1994), deny the fact that memory can be later recovered during a process of non-suggestive therapy, but both researchers voice specific areas of concern. They are sceptical of both memories recovered using certain therapeutic techniques (hypnosis, guided imagery, bibliotherapy, interpretation of dreams and physical symptoms) and memory recall that has been influenced by the use of self-help literature such as *The power to heal* (Bass and Davis, 1988). This book, which has had a significant influence on popular culture, suggests that if certain symptomatology is present, and despite the lack of memory, abuse is highly likely.

Loftus (1993) cites a number of studies, some conducted by herself, which add support to the concept of false memory by demonstrating that error in memory recollection is a common phenomenon, and that non-existent memories can be implanted into the minds of individuals, using various laboratory controlled methods (Loftus and Ketcham, 1994). Without going into precise detail of this "lost in the shopping mall" research, it has subsequently been criticised by others as being characteristic of research creating false beliefs about memory, rather than creating false memory themselves (Sivers,

2002). Consequently, this research has been seen, by some, to have limited value and to hold little relevance to recovered memory of trauma such as child sexual abuse. Loftus (1993), by drawing on the research of others, is unconvinced about memories, such as those of Lizzie and Jean, where recollections are retrieved from before the age of 3 or 4. She suggests that these memories could, in fact, be memories of things told to them by others. Working along similar lines, Lindsay and Read (1994) argue for the constructivist nature of memory, rather than memory operating on a straightforward process of retrieval. They contend that, certainly, within in the context of therapy, an individual's suggestions can lead, ultimately, to distortions and errors in recollection.

In addition to the perceived lack of scientific evidence confirming that the theoretical concepts of repression and dissociation are legitimate psychic processes (Mollon, 1996), Lindsey and Read (1994, page 326) assert that the following factors increase the possibility of a false memory:

- Long delays between the proposed event and the attempt to remember
- Suggestions that a particular event occurred
- The perceived authority of the source of suggestion
- The perceived plausibility of the suggestion
- The repetition of the suggestion
- Mental rehearsal of the events
- The use of hypnosis and guided imagery

Furthermore, these authors are dismissive of the emotional pain that often accompanies the recovery of the abuse memory, proposing, instead, that the distress reported by individuals around the time of recovery, (and as described by some participants in this study) is symptomatic of the process of "coming to believe" that event, regardless of whether it happened or not. Another argument that Lindsay and Read (1994) use to discredit recovered memory (particularly recall happening within therapy) is the significant

numbers of subsequent retractors. This issue is problematic and potentially a "red herring" in the sense that, under normal circumstances, there are a vast array of other factors that might predict a retraction, including, quite commonly, the degree of family pressure exerted upon the victim to withdraw their story (Mollon, 1996).

The issue raised by Jean, in relation the credibility of the recovered memory with regard to police and the legal system, can carry some of the same elements of scepticism described above. More commonly, situations involving recovered memory of child sexual abuse have reached the courtroom in the US, where cases have been brought either by the victim against the perpetrator, or by a retracting victim or third party (perpetrator) against a therapist (Gothard and Cohen Ivker, 2000). The role of the court is to establish historical truth, which is unlike the narrative truth described in the previous section and achieved through the healing process. Historical truth, according to Spence (1994), is marked by its contradictory and disconnected nature with the presence of the child's voice clearly embedded within it. It is free from a rehearsed and "polished" presentation, consistent with the continual working over of the experience in therapy, which, in the opinion of the court, makes the narrative less credible. Whitfield (2001) describes some of the strategies used by alleged perpetrators within the courtroom situation, to elevate their position in the eyes of the jurors and discredit the testimony of the victim. Before elaborating further on these strategies it is worth noting that many of these ploys are also prevalent in the prosecution of historical cases where the complainant has continuous or partial recall. They may also be relevant for the general public when assessing the overall validity of a narrative involving child sexual abuse, a factor that Lyn alludes to when talking about the general plausibility of her narrative for others.

Whitfield (2001) believes that often a defendant will submit factors relating to his (her) general character, such as being a church-goer or an "upstanding member of the community," in order to increase their credibility. Not infrequently the defendant will also present themselves as the victim of the "implanters of false memories" e.g. the therapists, the media, books etc. The

testimony of the victim, by contrast, will be undermined by attempts to call into question their mental health. Whitfield argues that, quite often, emotional destabilisation accompanies recovered memories (as can be observed in participants quotes in the previous section of this chapter), which can then be used to this effect. The victim may also be criticised for being unable to offer corroborative evidence such as eyewitness testimony, physical symptoms or medical record information, an absence of which is quite typical in child sexual abuse cases. Ulterior motives are proffered for the victim's so-called "lies" and other explanations offered for the victim's symptomatology prior to the recovery of the memory, such as marriage difficulties, for example.

Expert witness testimony is commonly taken from individuals that are associated with the False Memory Syndrome Foundation. Whitfield (2001) asserts that these witnesses, who are generally not clinicians, offer "pseudo-scientific versions" of published research data, such as that of Loftus and Ketcham (1994) and Lindsey and Read (1994). They demonstrate little understanding of the traumatic effects of child sexual abuse, and little knowledge of the psychic processes that serve to protect a victim's integrity in childhood. Whitfield also asserts that sometimes experiences of recovered memory containing descriptions of incidents that are perceived to be quite extreme, such as satanic and ritualistic abuse, are used as comparative substance to add an air of depreciation to the whole subject of recovered memory. The reality of the situation is that research data illustrates that satanic and ritualistic abuse are, clearly, an actuality for some children, and that amidst this incomprehensible adult behaviour children can develop dissociative amnesia to cope with these extreme abuses (Scott, 1998). For women like Jean, whose sexual abuse is consistent with ritualistic practices, and who witnessed events that some would consider to be extreme (but that others, particularly disabled people, would know to be highly likely) her experience sits within a societal discourse of disbelief, which transcends an individual's own tendency for personal scrutiny.

Whitfield (2001) argues that the upsurge in public interest in false memory discourse, and its associated attempt to re-define child sexual abuse as a

“memory problem,” has been, to date, the most sophisticated attempt by society to deny the problem and place it at a safe distance, once again. Saraga and MacLeod (1997) believe that the push towards pathologisation, by the addition of the word “syndrome” to the phenomenon of false memory, is yet another ploy designed to undermine the voices of women struggling to establish their narrative truth. Feminism, as already indicated, identify this discourse as another form of counterattack against women and their attempts to destabilise the patriarchal power structure of the nuclear family. Symptomatic of this concern, according to Gaarder (2000), has been the systematic depreciation of anything female, but more notably the victims, the therapists, the mothers and feminism itself. Whilst, by comparison, even when found culpable, perpetrators can escape relatively unscathed (Hoult, 1998).

Chloe raises, in her quotes, the subject of believability, both in terms of the issues created by her impairment and her general experiences of being parented. This meant that when she did encounter supportive questioning by the police, with regard to her experience of extra-familial abuse, she found it difficult to reconcile their approach with her own personal experiences. ADHD (Attention Deficit and Hyperactivity Disorder) has been the subject of conflicting professional debate for over the last two decades, with differing professional groups conceptualising the impairment in variable ways. Anti-psychiatry approaches, in particular, have emphasised the regulatory features of a social system, which attempts to modify conditions that fall outside the “norm” with regard to social and academic performance (Singh, 2002). In practical terms, the core characteristics of ADHD are considered to include: impulsivity (that can compromise personal safety), inattention and hyperactivity (Singh, 2002) and undoubtedly an unsupported family situation can easily become a negative experience for both parent and child.

Vitanza and Guarnaccia (1999) argue that for mothers, in particular, stress increases if the individual is socially isolated, unsupported by professional agencies, low in self-esteem, lacking in personal resources and sensitive to perceived criticisms regarding parenting skill, which can then manifest itself in depression. Certainly for Chloe, as can be seen in Chapter Three, page 104,

she describes these factors as pertinent issues for her mother whilst Chloe was growing up. This level of parental stress, then, has the potential to culminate in dysfunctional parenting practices with an increase in reprimanding interactions (McCleary, 2002) and comments relating to a child's truthfulness. Such negative interactions can impact upon a child's self-esteem and create a situation whereby the individual begins to question their own feelings and judgement. Child abuse, and an abuser's need to dis-empower the child and cover their own tracks, added another level of complexity to Chloe's situation. Notwithstanding the criticism levied against the police by particular groups of disabled women involved in the criminal process (Keilty and Connelly, 2001), the result for Chloe, when faced with a positive police interview experience, was disbelief that these professionals took her abuse allegations seriously.

d. Concluding remarks

For children, generally, it would appear that the beginnings of an ability to produce narrative that reflects an understanding of the self in relation to others occurs between the age of 2-4 years (Thompson, 2003) and is heavily influenced by the style and content of the parent-child conversation (Eder, 1994). In relation to a trauma experience, such as child sexual abuse, the child is unable to use the usual conflict-resolving function of narrative to develop and process the experience (Neimeyer and Stewart, 1996) since it falls outside their knowledge base and developmental abilities. This fact is illustrated by Josh's first quote with the second illustrating the consequence of "narrative blockage" for the development of the child's larger narrative:

"The first time it happened I just couldn't collate it, I just couldn't work out what was happening, I had no experience of that, I had no knowledge of it, all that blood, all that damage, and I think you switch off, it's too much."

Josh

"I went to school but I don't remember much about school, I don't know much about those early years because for the simple reason

that there was so much trauma going on in other places. When I look back, I can see that I wasn't so concerned about my disability because I was so wrapped up in the abuse, whereas if I hadn't have had the abuse then my focus might have been solely on the disability."

Josh

The difficulties resulting from an interference with identity formation are well documented in the previous chapter. Within this chapter it becomes apparent that when the usual defence mechanisms (dissociation) become less necessary and when external triggers are prevalent, the unprocessed sexual abuse narrative emerges, sometimes creating narrative chaos (Frank, 1995), but usually requiring some attention in terms of its integration into the coherent whole.

For most of the participants in this study, there had been partial or continuous recall of the abuse experience, but nevertheless the "wearing down" of dissociative defences, for some, resulted in the retrieval of other previously buried memories, and for all, brought the abuse experience into full focus. For two participants, who had developed dissociative amnesia in childhood, although being aware that "something was amiss," the piecing together of fragmentary sensory episodes created a narrative that contributed significantly to understanding previous thoughts, feelings and events. One participant commented on the continuing state of narrative chaos in their life, and others acknowledged the incomplete nature of their current narrative with the hidden potential to recover further memory. The recovery of an abuse narrative following dissociative amnesia, in particular, raised the issue of the believability of the new material for people in their close family network and made them ponder the plausibility of it for others in wider society. One participant raised an issue relevant to the interaction of impairment and abuse, which arose from dysfunctional family interactions and led to her own inability to recognise and validate her narrative truth.

The later and ongoing work undertaken by participants has included the reconstruction of the abuse narrative; a narrative which reflects a personal

reality (narrative truth), assists in the process of meaning-making and facilitates an improvement in general functioning. Essentially, this has been achieved via their involvement in therapeutic conversations, their discussions with members of the nuclear and extended family and their consultation of medical records, which have provided an additional validating source. As well as an ability to construct a “different and more empowering story” healing has involved, for some, the acknowledgement of the losses inherent within their narrative, particularly the loss of “childhood” and the loss of “self.” For a number of participants, recovery has involved the symbolic reclaiming of childhood and adolescence via the purchase of toys denied of them in childhood or via “acting out” in therapy. Some have attempted to reinstate the self, again, either symbolically via the use of mirrors or photographs, or via their involvement in self-affirming activities such as research. In essence, this work has been experienced as painful, but recognised as necessary for distancing the self from the original trauma experience.

The desired end result for participants, which has been achieved by different participants to varying degrees, is the attainment of a coherent narrative that joins dissociated past life events together so achieving a sense of narrative continuity (Sarbin, 1986). From a position of being unable to, truly, make sense of past experiences and behaviours, narrative continuity has conferred an ability to reflect upon and evaluate the experience of child sexual abuse, and formulate a sense of narrative identity (Baeger and McAdams, 1999). As is apparent, the emphasis within this chapter has been on the participant’s production of an abuse narrative, with disability taking secondary importance. This factor relates, I believe, to the early stages of the interview process itself and the collaboratively produced talk, which Rapley (2001) describes as opening up certain pathways in the listener’s thinking when analysing the data.

Finally, and in terms of the overall theoretical positioning of this chapter, I need to comment on the constructionist nature of narrative production and the discourse that surrounds it, and my privileging of a social constructionist viewpoint. This is despite reference to, and belief in, the operation of certain

psychoanalytic concepts functioning within it. The social environment, for participants in this study, has both impeded narrative construction and the development of a healthy narrative identity, but has also been responsible for the facilitation, later, of the reconstructed and reflective narrative. These conversations, which have contributed to the narrative production, have both promoted healing and encouraged the development of an authentic sense of self.

CONCLUSION

One of the major objectives of this piece of work, as detailed in the original aims of the study, was to give voice to the experiences of individuals who have been silenced by the experience of child sexual abuse, in the first instance, and then once again by societal discourse, which relegates the experiences and opinions of disabled people. Through the clear articulation of their ever-evolving personal narratives, participants, I believe, have extended our existing knowledge of this subject area and have offered unique perspectives, which require society's focused attention. The participants, five of whom were women and two men, all told reconstructed stories of abuse from states of continuous recall, partial remembering or recovered memory from a prior state of amnesia, with all of them feeling that the recovery process continues to this day (Chapter Four, pages 116-117). Different individuals identified themselves as being at different points in the healing process which can best be observed in the struggles that some individuals have with the limitations offered by the survivor identity (Chapter Four, page 115) and others have in dealing with the ongoing problem of breakthrough reliving experiences (Chapter Five, page 197). For one participant, it was painful to even acknowledge that there was, indeed, some linkage between disability and child sexual abuse (Chapter Four, page 115).

This conclusion does not attempt to summarise the contents of the chapters since that would be repetitious but, instead, begins by weaving together the complex and, sometimes, contradictory relationship between disability and sexual abuse. Despite the fact that each participant's circumstances differed in a variety of ways, I endeavour to highlight the key pressure points where disability and sexual abuse interacted and difficulties were exaggerated. This will be achieved by drawing out the specificities of the relationship for each of the individuals concerned. This section of the conclusion includes both current adult perceptions of childhood experiences and the problems that the experiences are seen to create later, with regard to identity formation and narrative production. I will then discuss the research methodology, the

advantages it conferred for studying this type of research subject, the issues involved for participants in producing a different type of story and the particular ethical dilemmas that it presented for me as a researcher. The theoretical positioning of the research will be considered next, as will its relativity to the range of discourses that currently surround this area of work, and how it has contributed to and expanded these debates. The conclusion will finish with a perspective on the repercussions of this research for current policy and practice, both within local authorities and the National Health Service.

a. Disability and child sexual abuse: “the double whammy effect”

Several of the women perceived themselves, as children, to be a “problem” or a “burden” to their families. Jean saw this problematic identity reflected in the visible pain her mother experienced when dealing with a child whose body conflicted with an idealised norm and who required medical interventions (Chapter Four, page 146). May saw, and was told by her mother, that her “problem status” had contributed to the breakdown of her parent’s relationship early on in May’s life (Chapter Three, page 102-103). She also felt that it was probably responsible for her subsequent institutionalisation in a residential school. For Lyn, her parent’s difficulties in accepting their child’s impairment manifested itself in their encouraging her to hide her hearing aid, in the same way that her mother disguised the fact that she had a missing limb (Chapter Four, pages 126-127). The imperative was to underplay any sense of difference and Lyn described feeling guilty and apologetic, within her family, a large percentage of the time (Chapter Three, page 103).

The sense of indebtedness created in May by her family, who later sought her return from residential education, was one of the factors that precluded her ability to disclose her subsequent sexual abuse by her stepfather (Chapter Three, page 102). In Lyn’s situation, she believed that her devalued position within her family led to a personal belief that she deserved to be sexually

abused and that this was something that she could do well, by comparison to a non-disabled peer who was also being abused but, unlike Lyn, was failing to function in the school setting (Chapter Three, page 103-104). Josh, who did not talk about feeling particularly devalued in his family in relation to his disability status, believes that, because of his need for personal assistance with intimate care tasks, his impairment provided the necessary opportunities for sexual and physical abuse to occur (Chapter Three, page 88). This was a view also shared by May who required physiotherapy from family members (Chapter Three, page 88). Later, Josh's impairment fulfilled the criteria for his placement in a residential school. This was used as a method of dealing with his mother and doctor's suspicions of sexual abuse and was felt, by Josh, to have deprived him of an appropriate level of education. Additionally, this placement also exposed him to further sexual abuse by an older child resident (Chapter Three, page 69). As a child, a relationship was probably being formed, in his mind, between impairment, punishment and child abuse. Additionally, May made linkage between institutionalisation and an inability to disclose child sexual abuse (Chapter Three, page 68) and medical objectifying procedures and the creation of the potential for later sexual victimisation (Chapter Three, pages 60).

Thomas, who had undiagnosed learning issues, believed that his stepfather singled him out for sexual abuse because he was perceived to be unable to offer the same level of resistance as his stepbrothers and stepsisters (Chapter Three, page 85). Some of these siblings, he later found out, were also being abused. For Thomas, and as is to be expected, the sexual abuse exacerbated his learning difficulties. Chloe felt that her family circumstances illustrated how the pressures associated with an undiagnosed and unsupported impairment can easily lead to a significant deterioration in the parent-child relationship. In her case, she contended that this was responsible for her emotional availability, her need to seek out adult stimulation outside the home environment and her subsequent involvement in a paedophile ring. Chloe also argued that her impairment and associated difficulties with memory could have singled her out as a suitable target for paedophiles (Chapter Three, page 87). Similarly, Lyn felt that her difficulties with communication could have

provided a similar function for the extra-familial abuse that she also experienced by a family friend (Chapter Three, page 87).

Both Lizzie and Jean had recovered their memories of child sexual abuse from a previous state of dissociative amnesia (see Chapter One, page 14). Prior to the recovery of their memories, both spoke of a significant degree of emotional turmoil within their lives, with Lizzie attributing some of these emotional difficulties to the effects of disablism both within the school setting, where she was excluded by her peers, and subsequently within her work environment (Chapter Four, page 148). Both Lizzie and Jean felt that the recovered memory helped them to make sense of previous life experiences and, for Jean, it provide the impetus for trying to achieve some degree of connectedness within her emotional world. Lizzie, who spoke of witnessing other non-disabled children also being abused on the same hospital ward, felt that she was not singled out specifically because of her impairment, but, rather, because of her availability (Chapter Three, page 88). Jean, on the other hand, felt the opposite and believed that some of her abuser's "purging" type behaviours were symptomatic of what disability represented for the clergy within the Catholic Church (Chapter Three, pages 86). For other members of staff, she believed that their abusive behaviour and, in one instance, their life-taking actions were associated with the low value that they attached to disabled children's lives.

For all of the participants, identity formation and identity enactment had been a complex and confusing matter. Similar to the methods used by non-disabled children, they all employed a series of dissociative behaviours to deal with the feelings generated by the abuse experience, either at the time that it was happening or after the event (Chapter Four, pages 147-152). Here, I am keen to echo and underline the opinions of Young (1992) and Warner (2001) who contend that rather than viewing these behaviours in psychopathological terms, as has been the tradition within psychiatry, these behaviours are, in fact, "healthy" expressions of pain and confusion to an unhealthy family situation. Josh and Jean's views draw particular attention to one key dynamic that may be operating for some sexually abused disabled children. Already

having to contend with the notion of a “bad body” created by the experience of disability, their feelings are compounded by the sexual abuse experience. The abuse experience aggravates their negative perceptions of their body and its worth, and further compromises their emotional and psychological well-being (Chapter Three, page 101, Chapter Four, page 146).

Despite this, inherently, disadvantaged starting position all participants continue to successfully “carve out” a series of identities, many of which are seen to have an empowering influence on their lives. For both Lizzie and Chloe, their personal and political beliefs offer validating perspectives that counter any tendency to individualise the issue of child sexual abuse. For Chloe, in particular, the understanding gained from the social model of disability and the associated concept of oppression has been readily applied, with positive effect, to her experiences of abuse (Chapter Four, page 125). Some participants, such as Thomas, wholeheartedly embrace the survivor identity (Chapter Four, page 114), feeling that it offers an accurate description of the challenges he has faced and the achievements that have been made. Lyn, on the other hand, feels that certain identities can be conflicting in nature, with the societal discourse that surrounds the issue of impairment creating some opposition to the acquisition of yet another stigmatised identity i.e. the survivor identity (Chapter Four, page 115).

Forging intimate sexual relationships has been problematic for both male and female participants. Heterosexual females have had to manage their asexual objectification either in terms of the difficulties they encountered when trying to pursue a relationship, in the first instance, or the risk they face of meeting abusive men (Chapter Four, page 133). For May, in adolescence, she describes how her experience of asexual objectification (Chapter Four, page 132) conflicted with the reality of having to provide cover stories for any potential pregnancy (Chapter Four, page 133). In adulthood, she experienced a series of violent partners, but this factor is felt to be an emotional consequence of child sexual abuse and her inability to prioritise her own needs (Chapter Four, page 136) rather than her disability status. Whilst this may be the case, disability has the potential to complicate the matter further

and widen power differentials. In relation to heterosexual men, the main issue was centred on the resolution of a homosexual learning experience with a heterosexual identity (Chapter Four, pages 133-134). For many of the participants, recovery has also involved the creation of a narrative identity and an ability to produce an coherent and authentic narrative of the self, which demonstrates a capacity to reflect upon and evaluate their experience (Baeger and McAdams, 1999), an issue which will now be considered further in this next section.

b. Narrative and methodological matters

A narrative approach has provided the necessary flexibility to capture the depth and richness of these individual's life stories as they endeavour to create a life story account that offers explanations for the past and a way forward for the future. Their stories have involved a re-evaluation and re-construction of the abuse memories and the relinquishing of any possible residual feelings of blame and responsibility (Chapter Five, page 173). Some participant's healing has involved a re-working, in a varied and imaginative fashion, of the losses that they perceive were incurred by the experience of child sexual abuse. Some of these healing stories involve re-parenting in the context of a formal therapeutic relationship (Chapter Five, page 183) and others describe a nurturing of their neglected "child self" by an engagement in child-like pursuits and the purchases of children's toys (Chapter Five, pages 183-184). Jean and Josh spoke of their loss of "identity" or their loss of "self," with both being involved in reparative work involving such things as self-portraits, the use of mirrors, repositioning of childhood photographs and their involvement in the narrative research process (Chapter Five, page 184). A number of participants are actively involved in re-writing their experiences in story format or poetry (**Appendix G**).

The process of being able to tell or write this reconfigured narrative has been precipitated, for most participants, by circumstances that have permitted or, sometimes, forced their engagement with a previously dissociated lifestyle

and an incoherent narrative. This re-engagement process created, for many, extremes of emotional destabilisation and a degree of narrative suspension (Chapter Five, pages 192-197). At the time of writing, this state of narrative limbo and absence of control continues to permeate one participant's life (Frank 1995).

Some of the participants' stories include tales of problematic relationships with their birth families, where sexual abuse created tensions, conflicts and uncertainties. Thomas's mother, for instance, has chosen to dismiss her adult child's abuse narrative and idealises, instead, her deceased partner and former paedophile (Chapter Four, pages 119-120). May's mother, who was aware of the abuse at the time of its occurrence, continues to deny her daughter's reality (Chapter Four, page 120) creating, for May, a continuing sense of worthlessness and a fear of confronting her sister in case May's childhood silence facilitated her sister's abuse (Chapter Five, page 175). Other participants' mothers have pledged their support, and siblings have responded by either sharing their abuse stories or burying the secret even further (Chapter Five, page 174). This range of family reactions, however, has not deterred participants from continuing to vocalise their narratives with some degree of determination.

The two experiences of recovered memory forced me to engage with the recovered memory/false memory debate. This issue of "truth" required a distinction to be made between narrative truth, which is formulated within a therapeutic context, and historical truth, which carries some factual and legalistic connotation. These two individuals reconstructed their abuse narratives from fragmented sensory episodes (Chapter Five, page 191 and page 193) and, despite the varying reactions of close family members to their disclosures, Lizzie and Jean's clarity about the validity of these memories have never faltered. This is a factor which may have some relevance to the general societal invalidation of recovered memory and may, or may not, have some relevance to the abuse narratives of disabled women who have to state their case louder, clearer and with more voracity than others. Nevertheless, where the overlap between disability and narrative disclosure becomes more

apparent is in the difficulties that Chloe experienced in believing and validating her own experience and memories of sexual abuse (Chapter Five, pages 206-207).

My own personal and professional narrative will have had some relevance to the collection of the data and, more specifically, what participants felt able to share on the day. In the early stages, at least, I perceived my status as a disabled person to have helped in terms of my identification as an “insider” (Vernon, 1997) despite becoming aware of the fact, fairly early on in the process, that my identity as a mother of a disabled child offered the potential for curtailment of a free and unbiased exchange on the subject (Chapter Two, page 42). I shared personal autobiographical material where I felt it was appropriate and was aware of needing to strike the right balance between building a trusting relationship and resisting any temptation or invitation to feature too centrally within the discourse. I have concerns as to whether, in reality, this balance was achieved. I was aware that my career history and personal politics indicated a particular researcher “standpoint,” which was reinforced at certain junctures in the process, and appreciate that this “standpoint” may have cut off certain avenues of exploration. The use of the “time line,” in itself, appeared to have helped facilitate the sharing of complex material. This tool, however, may also have imposed a structure that offered too many restrictions for the participants and failed to recognise an ability to manage their own narrations.

Self-evaluation and rumination was a constant feature of the work; so too was an awareness of where our individual needs might conflict, e.g. my need to gain a comprehensive narrative account and their need for protection from over-exposure. Consistent with the emancipatory research model, I was conscious of political obligations to involve participants as much as they cared to be involved, offer them every opportunity to make alterations to their narrative and comment on the substance of the chapters. Ultimately, I wanted to produce a written document that had some practical benefit to their self-empowerment (Priestley, 1997). In reality, only the participants themselves can comment on whether I have achieved these stated aims. In ethical terms,

the research imperative was to be thoughtful, sensitive and respectful of where they were at in terms of their own healing process. I was conscious of the potential repercussions of participation in such a sensitive area of research. Within the analysis, I have worked hard to counter some of the pathologising and individualising discourses that surround both the subject of child sexual abuse and impairment. Despite being a novice researcher, and despite the inherent difficulties detailed above, I hope that the experience was not too limiting and I trust that I have represented their views and their associations with some degree of accuracy.

c. Theoretical considerations

This thesis is firmly embedded within a social constructionist framework and a belief that meaning is constructed within the context of our relationships with others and the discourses that regulate them. The qualities and substance of this dialogue are culturally and historically situated (Gergen, 1999), with a scientific and medical viewpoint being valued and prioritised above all others (Chapter Three, page 62). A limited number of “acceptable” identities arise from these exchanges, with those identities that deviate from the “norm” being classified as other/different/inferior (Burr, 2003). Clearly, impairment falls outside the acceptable norm (Chapter One, pages 15-18) and within a societal classification there are also further gradations of acceptability that complicate the matter (Appleby, 1994; Vernon, 1999). I argue that, within this overall approach, there still exists scope for a theorisation of the “self” (Callero, 2003) and an individual’s potential to act with agency and resist their oppression. The thesis, therefore, rejects the determinism implied in post-structuralism and sees individuals, despite their experiences, being able to rise above their oppressions and gain a more autonomous mode of functioning. This becomes particularly apparent when considering the capabilities of participants in this study to reframe the abuse experience (Chapter Five, pages 173-175 and pages 181-185) and assume the survivor identity (Chapter Four, pages 114-121) despite its conflicting constituents. Their autonomy is further evident in

the personal work undertaken to allow them to positively and confidently occupy a disability identity (Chapter Four, pages 125-127).

The analysis of the data also draws from a number of other theoretical ideologies (Chapter Five, page 187) despite the fact that some of these approaches are oppositional and politically conflicting constructs, e.g. the simultaneous use of social constructionism and psychoanalysis. Clearly, psychoanalysis, and its associated offspring, is an example of one of society's prioritised discourses, which has been an oppressive force in some disabled people's lives (Corker, 2003; Swain et al., 2003). However, this thesis is ostensibly data led and for some participants in the study this type of therapeutic approach has been helpful. The utilisation of this theoretical concept, in my opinion, has both widened and deepened the texture of the analysis.

Consistent with a social constructionist theoretical positioning is the application of the social model of disability, which, by the reorganisation of language (Swain and French, 2000) and the highlighting of oppressive forces in society that work against us (Barnes, 1996), reconstructs the meaning attached to disability in western society. This thesis extends materialist disability perspectives, however, by illustrating the range of ways in which disabled children are invalidated by societal attitudes and practices. This invalidating discourse has been shown, in this work, to create dysfunctional organisational cultures and practices that work, often in an insidious fashion, to marginalize or negate disabled children's emotional well-being, so placing them in situations of unacceptable risk. Clearly, extended periods of hospitalisation and residential education are examples of such practices, where the likelihood of encountering paedophiles is increased and the parent-child bond is compromised.

Equally, as already referred to in a previous section, this study illustrates how devaluing societal discourse can impact on family life, influencing the attitudes and behaviour of parents, so creating, for that child, feelings of insecurity and indebtedness. These feelings can then manifest themselves in

the disabled child's inability to "speak out" about the abuse experience. They can also precipitate a need for others to indiscriminately seek out adult attention outside the home placing them at risk of extra-familial abuse. The theoretical approach therefore reframes the traditional perspective on this subject by rejecting an individualising approach that links causality to the perceived shortcomings created by impairment and posits, instead, a perspective that reformulates the issue in terms of the broader social context of invalidation and indifference to disabled children's welfare (Calderbank, 2000).

By using a narrative methodology, this thesis has prioritised personal experience and has highlighted the ways in which disability, impairment and child sexual abuse have interacted and shaped the lives of the participants concerned. As a result of the combined impact of these entities, it has paid particular attention to the embodiment and expression of emotional pain for these individuals. The methodological approach therefore accords with the writings of disabled feminists who argue that the "personal is political" (Morris, 1992) and has demonstrated, through the deconstruction of participant's narrative, that the political dimensions of the story inevitably reveal themselves. The research adds to the small, but growing, body of work written by disabled people about the experiences and opinions of other disabled people.

I would argue that this thesis problematises the victim-survivor dichotomy that pervades child protection literature, by arguing that these identities have the potential to become limiting and oppressive categorisations. The participants in this study were clearly survivors, but tended to oscillate between these categories depending on the triggers prevalent in their immediate environment. It was possible for them, using this limiting discourse, to be "survivors" one day and "not quite survivors" the next (Chapter Four, pages 116-117). This debate highlights the limited number of identities available to individuals who have lived through this type of experience. In reality, the only other alternative on offer appears to be the perpetrator identity.

This thesis also draws attention to the complications implicit in being a disabled survivor of child sexual abuse. As illustrated, the usual difficulties of formulating an identity and constructing a narrative are aggravated by the experience of disability (Chapter Three, pages 101; Chapter Four, page 146). Despite this fact, however, research literature relevant to the disabled child or adult's perspective rarely presents itself. Much of the child abuse research takes the form of prevalence studies, which use a quantitative methodology and the complexities of individual experiences are rarely exposed. I would also contend that the thesis extends the parameters of feminist debate and the theorisation of the body by positing disabled women/young people as individuals who can experience both asexual objectification and sexual violation simultaneously (Chapter Four, page 132 and page 133), potentially perpetuating a "bad body" identity and a sense of further psychological disruption.

d. Implications for policy and practice

Engaging with the complex narratives of disabled survivors offers a lucid appraisal of the consequences for the individual concerned, and represents the liberation of the voices of a previously silenced and devalued sector of society. The narratives also offer a solid base for challenging current policy and practice, mirroring some of the previously expressed concerns of disability writers (Shakespeare, 1996; Morris, 1999). As already indicated, and in addition to the risk factors associated with the cultural beliefs that permeate large organisations, this thesis adds weight to the argument that disabled children's family circumstances and care requirements can place them at an increased risk of abuse. This issue, undoubtedly, requires more focussed attention by those invested with the responsibility to monitor and promote disabled children's well-being.

As prevalence studies indicate that disabled children are over three times more likely to be sexually abused than their non-disabled peers (Sullivan and Knutson, 2000), local authorities, for one, need to pay particular attention to

their disparate professional practices that contribute to the perpetuation of the problem. Some of the most obvious manifestations of local authority indifference can be best observed in the range of discrepancies that continue to exist in relation to the investigation and assessment of child protection concerns. Participants in this particular study raise other issues relevant to:

- The support required for parents caring for children with an undiagnosed impairment.
- Support required for the parenting practices of those caring for disabled children with diagnosed impairments.
- The monitoring of a child's well-being once placed in residential care.
- The methods of communication used by social workers to obtain a child's unbiased and impartial viewpoint.
- The need for consistent professional practice relating to the appropriate management of child protection concerns within schools.
- The need for disability training in mainstream schools which genuinely promotes an inclusive ideology.
- The need for training in mainstream schools, which is relevant to the identification and conceptualisation of hidden impairments such as Asperger's syndrome.
- The facilitation of support systems for that child, which negates the potential for "othering" by teachers, the child's peers and their peer's parents.

As far as hospital settings are concerned, the main issue raised relates to the culture of the organisation. An improvement in existing systems is indicated which facilitates the identification and management of unhealthy cultures that exhibit objectifying characteristics. For many of these issues, relevant to both local authorities and health settings, the problems can begin to be addressed by disability training, founded in a social model approach, which demands a degree of reflexivity and a challenging of personal belief systems. A good starting point, I would contend, rests with those professionals who both assist in the birth of a disabled child and then support parenting back in the home

environment. Similar to Thomas (1998), I would argue that much could be achieved here by challenging the “tragedy model” of disability and promoting a more positive and empowering model of parenting for disabled children.

APPENDICES

Appendix A

Are you interested in taking part in an important area of research

Disabled PhD student at Northumbria University is looking at the sexual abuse of disabled children using the life stories of adult survivors and would like to hear from any disabled adult interested in sharing their stories and opinions. All information you give to the researcher will be confidential and you should have already spoken to someone about the abuse. For further information contact: Martina Higgins, PO Box 606, York YO32 5YT or e-mail: martinahiggins@tesco.net

Breaking silence

The sexual abuse of disabled children is pervasive, but few are willing to discuss it. Martina Higgins investigates

Disabled children are two to three times more likely to be sexually abused than non-disabled children. Like non-disabled children, their abusers are relatives, caring professionals and adults involved in organised paedophile networks.

So why is it that we never hear cases reported in the national and local media? Why is there a silence around the subject? And why are local authority policies and legislative frameworks woefully inadequate when dealing with the problem?

Some researchers believe that society gives perpetrators a licence to abuse disabled children. The stigma of disability and the devaluing of disabled people's lives may make child protection

requirements for disabled children secondary to non-disabled children. Denial is also an issue.

Damaging attitudes prevail, such as: "Who could harm someone so unfortunate?"

It is obvious why disabled children are vulnerable. They are more likely to live in segregated institutions with power hierarchies. They are more likely to depend on a number of carers for various tasks and activities, so there is more chance that they will meet sexual abusers who expertly lever themselves into these jobs. Non-verbal children cannot always tell somebody about sexual abuse because adults may not share the same communication system as the child, or the system itself lacks a



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Code of silence: the voices of all children need to be heard

vocabulary for abuse. There is a local and national shortage of interpreters for children with hearing impairments. All these factors delay intervention and add to the likelihood that someone will choose a disabled child to abuse.

As society grows more aware of the vulnerability of children, why do disabled children receive a second-rate service?

In 1999, researcher Dr Jenny Morris looked at the flaws in the UK child protection system by studying three local authorities. Her findings were grim. One authority thought it was necessary to get it right for

non-disabled children before considering disabled children.

There was also little understanding of disability in professionals dealing with child protection investigations and poor understanding of child protection issues in professionals working with disabled children and their families.

There was no monitoring of children in short-term or longer-term respite placements using care plans or review meetings. Very rarely were disabled children asked for their views.

Without a "shake up" of services, disabled children will continue to fall through the

child protection safety net.

As Margaret Kennedy,

trainer and consultant on abuse and disability, says, "It is only when practitioners address their own prejudices and attitudes towards disability and begin to develop truly personalised services, tailored to the exact requirements of the child, that things will change."

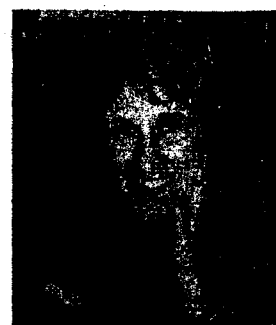
Above all, disabled children need to be heard and society has a responsibility to make this happen.

Researchers must play their part, too. It is more important to focus on the experiences and views of disabled children and adults than to collect data from files and professionals. Their voices are the ones that matter.

Martina Higgins is a disabled PhD student at Northumbria University. She is looking at the sexual abuse of disabled children through the life stories of adult survivors and would like to hear from disabled adults interested in sharing their experiences. Participants should have already spoken to someone about their abuse. Material will be kept confidential and participants will be fully informed and their agreement sought about storage and publication. Contact Martina Higgins, PO Box 606, York YO32 5YT or e-mail: martinahiggins@tesco.net

Appendix C

Martina is at University. She is doing some research (finding out). She would like to know if anybody can help her with this work. It is about child abuse.



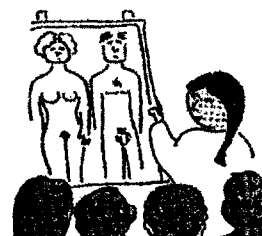
Child abuse is wrong.
Child abuse happens when an adult hurts a child by beating, punching or burning them.



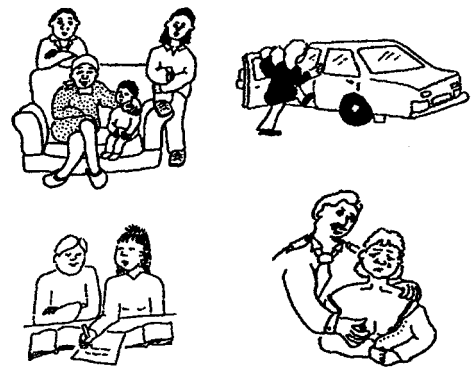
Child abuse also includes sexual abuse.



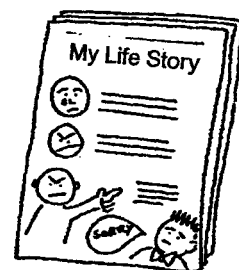
Sexual abuse happens when an adult touches a child on their private parts (breasts, penis, vagina, bottom)



The adult could be a father,
mother, uncle, teacher,
care worker, taxi driver etc.

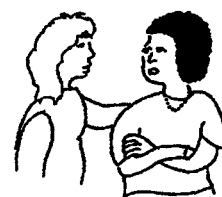


I am looking at the life stories of
disabled adults who have been
sexually abused as children.



If this has happened to you and you feel you would like to tell Martina
your story you can do it in the following ways:

Face to face



Tape recording the story



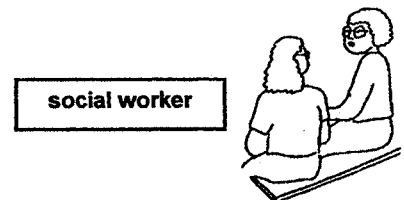
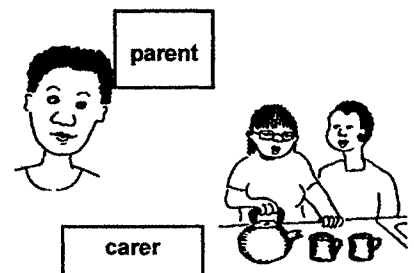
Writing the story



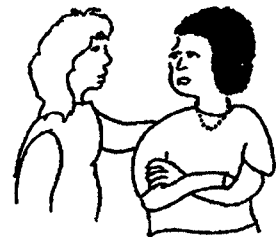
Anyway that's okay for you



Martina would need to know that you had already spoken to someone else about your abuse. This could have been your parent, carer, social worker.



Martina would also need to know that you had someone to support you when you take part in the research. The support person could take part in the interview.



If you think you can help Martina or want more information then ring People First:

telephone: 01904 431313



Appendix D

PROJECT INFORMATION SHEET

Title of the research project

To look at the lives of disabled people who have been sexually abused in childhood using the life stories of adult survivors

Aims of the project

1. To collect information from participants about their life story, including their experience of child sexual abuse. To establish how the participants made sense of this experience
2. To further explore their thoughts on:
 - a. What put them at risk of child sexual abuse
 - b. Why adults abuse disabled children
 - c. How sexual abuse has effected their lives
 - d. Whether non-disabled children would have the same types of problems as a result of sexual abuse
 - e. What strategies they have used to cope with the experience
3. To produce a piece of work that increases public awareness of the vulnerability of disabled children to the experience of sexual abuse. To give disabled people a voice and demonstrate their strength in dealing with such an abusive experience
4. To produce material that is accurate and acceptable to the participant

What does the project involve?

1. Stories could be told in a number of face-to-face interviews, which could be held at a location of the person's choice
2. Or they could take place:
 - a. On the telephone
 - b. By the person writing their story
 - c. By e-mail
 - d. Using a Dictaphone
 - e. Any other way, or any other combination the person feels happy with
3. The researcher would need to know that the participant has already spoken to someone about their abuse and has a good support network, with somebody to talk to before, during and after the interview
4. The researcher would share all her transcripts with the participant and the participant would be free to change, delete or add information
5. The participant could, at any point, decide not to be involved with the project

Confidentiality

1. All information shared by the participant would be confidential to the researcher and her supervisors
2. All tapes and notes produced in the interviews would be stored in a safe place and be destroyed or returned to the participant when the project was finished
3. In the writing up of the project, the identity of the participant would be disguised

About the researcher/interviewer

The researcher is a PhD student at Northumbria University and is supported in her work by two supervisors who give her advice and guidance. She is a disabled woman herself, has a five-year-old disabled daughter and has had personal experience of the varying attitudes that exist in society in relation to disability. She was a Social Worker and worked mainly in child protection for both the N.S.P.C.C. and the Local Authority. She has worked both individually and in groups with survivors of sexual abuse.

Appendix E

Ethical guidelines for interviews with project participants

Consent

1. Consent will be obtained from the participant and a consent form completed
2. Several explanations of the research will be given, with the researcher fully aware of what they are agreeing to
3. If the interview takes place in the form of a face-to-face interview, permission to tape record the interview will be sought from the participant

Confidentiality

1. Everything that the participant says in the interview will be confidential to that interview and only be shared with the researcher's supervisors
2. Extracts from the interviews may be quoted verbatim in the finished document, but the identity of the participant will be disguised
3. The tape-recording and any other material which may identify the participant, used during the course of the research project, will be destroyed at the end of the project or given back to the participant if requested

General issues

1. The participant will be given full control over the process, including how they want to give their information
2. Participants are at liberty to cancel interviews, stop sessions mid-way, refuse to talk about certain topics, or ask for the tape recorder to be turned off
3. Participants can withdraw their consent to the researcher publishing their material at any time

Appendix F

Consent Form

Please tick the appropriate boxes

1. I would like to take part in you research project ☐
2. I have changed my mind and would not like to participate ☐
3. I will participate using the following method:
 - a. Face-to-face interview ☐
 - b. On the telephone ☐
 - c. Via e-mail ☐
 - d. Using a Dictaphone ☐
 - e. By writing my own story ☐
 - f. Another specified method ☐
4. I have a support person I can talk to before, during and after the project has finished ☐
5. I am prepared to give details of that person ☐
6. I would like to talk to a counsellor from an agency that is experienced in talking to survivors of sexual abuse ☐
7. I do not need counselling, but would like a contact number in case I change my mind ☐

All information will be confidential to the interviewer and her supervisors. Your permission will be sought regarding storage and publication of material

Name	Address
Signature	Date

Form to be returned to: Martina Higgins, PO Box 606, York YO325YT

Appendix G

A selection of poetry written by Chloe and Thomas

Telling

I told my friend
she believed every word
and nothing happened.
I told my friend
I did not die
fall into a black hole
or get eaten by monsters.
I told my friend
so she can tell it back
it seems less crazy
coming from her.
I told my friend
and she knew a book,
a poem, a song, a site
and who to talk to.
I told my friend
then a counsellor,
my family, the police
and now I'm telling you.
I told my friend
"the monster may appear"
but she said "come on then!"
and it ran with fear.
I tell my friend
because she is
not afraid
of monsters.

Written by Chloe

Bingo caller

You had to wait for mother to go to
bingo before you got close to me.
I believed you when you told me that this
was love.
So easy for you to cover your evil and
dirty tracks.

My tears were looked upon as a childhood
tantrum.
The smack was deserved, needed and well
delivered.
I could not say anything to convince you
otherwise.

I would dread with all my heart those bitter
Tuesday nights.
A bright room would soon become dull with
a deep twisting fear.
Where was my place of comfort and safety?

On your return my problems remained hidden
by his lies.
Winning a line or house was the only subject
on your lips.
You had a hundred reasons for my terrible and
upsetting behaviour.

I, on the other hand, had no excuse to give for my
Tuesday night outburst.
My bed was soon occupied so the damage that he
had done was not on show.
Try to comprehend what you never saw or understood.

Did you win anything at that smoked filled hall on a
Tuesday night?
What was your long term gain compared to my overall
loss?
The caller is silent now, the ping-pong balls have no
meaning anymore.

Written by Thomas

Seasons of indecency

I contemplate a distorted vision of affection
that so often became a reality,
buttocks pressed firmly against the chair
seeking protection.
Shall I despise the silence of my screams, the
lack of tears,
I remember those nicotine-stained fingers caressing
locks of my hair.

Did my age rob you of your one secret desire?
What now, when, where will your grotesque
act of love begin?
In my fifteen summers I experienced a hundred
seasons of indecency.
My heart would race with the creak of a door in
mornings' first light.
I still found my nights flowing with an uneasy,
shallow sweat.
I will wait for her, the nemesis will call and then,
and only then, will I know that this is over.
That will be the time for the seasons of indecency
to come to a close.
Golden leaf with shade of red will fall from an azure
sky.
I will run hand in hand with the children of the lost,
together we will find a route out of the maze that you
created.

Written by Thomas

An ode to culpability mine

Culpability began to haunt my
every waking hour.
How the sea of shame enveloped
my whole being.
No rest for the wicked nor the
Innocent.
Through my lack of resolve your
guilt became part of me.

Resistance never rose to the
surface of that raging sea.
Oh how I lost myself amongst
the rocks and the screaming gulls.
I found no one.
Effort could not save me,
I did not want a rescue,
drown in an inch of denial
on the edge of a wind swept
shore.

Drifting on a tide of bitterness
with the flotsam and jetsam of
childhood.
Waves crash, turn and roll, fall

taking me deeper to the grave.
Above propellers slash the ocean's
skin as I fight the current.
Too strong, too strong is the guilt
that pulls me, drags this child twirling
to the stingray's nest.

Written by Thomas

The poor circulation of love

How frail is he that was so
strong and tall.
Hands tinged blue with the
poor circulation of love.
Mind forgetting knowledge
that came from cheap paperback
books.

How weak is he that once led an
empire of adulterers.
Chest hollow with his favourite
brand of John Players.
Hot tea with cold legs rapped in
tattered mock leather slippers.

How thin is he that grew so fat
off the backs of colliers.
Drank stout with country and
western on a Saturday night.
Hands trembling thanks to his
out of shape lungs and the
dance.

How ill is the dying old man
that now claims to love god.
Seeking forgiveness and finding
no reply from his victims.
Blood thick with the rich food
that the devil cooked.

How pathetic is he who was the
rod of steel.
Tattoos fade, thick and distorted
like his passing life.

Care from a few and hate from many
will be your testament.

Written by Thomas

Voice of age

Daffodils always remind me of
your death,
two golden flowers placed next
to your cold, pale face.
One eye open and the other closing
out life,
the clatter of blue hospital tea
cups and the voice of age.

The arm of comfort was swift to
ease round mother's shoulders,
tears fell into the palm of my
hand but failed to touch my heart.
May, spring and an egg-yolk yellow
sun at the window,
death has added a final twist to
an already twisted soul.

The waiting room becomes a temple
and we the faithful pray,
swapping corners of our minds in
the memory of your deep affection.
No more secret moments or stolen
kisses,
just stillness and white
sheets.

Written by Thomas

A day in the life of me

The first sound is always the one to
hurt my ears,
a hectic rush along litter strained streets
with my heart and soul to school.
This is a day in the life of me,
the one you find so hard to understand.

I always return at the same time in order

to check the mail,
brown envelopes are the most appealing
as they lie on the mat.
Then I drink tea and roll a smoke in my
warm hands,
conversation is always about the trip to
school and if he cried.

Then my mind starts the process of finding
something to worry about.
By the time I have eaten lunch I am
convinced I have a heart problem,
then again it could be a problem with my
brain or lungs.
This is how I live, the constant need to find
a method of self torture.

The night is fine due to a natural history
documentary and an anti-depressant.
I have to admit I enjoy the feeling of an
empty head, full of nothing.
Sleep is the next problem that I face but
I will drift off,
the morning is only six hours away and I
will have plenty to worry about.

Written by Thomas

Story work produced by Jean

My Story

This is the story of what happened to me in 1965. These events have haunted my entire life, flavouring my inner self like a bad smell that I could never track down. What I have is a collection of remembered sensations, images, sounds, smells, dreams, nightmares, inaccessible words and intense overwhelming feelings. I was in the second year of my life. It has taken me many years of hard work to put them together into an understanding of what happened in that hospital in 1965.

I remembered being abandoned by my parents in a place filled with the smell of anger, fear and pain. I remember being hungry and thirsty, I remember being cold, I remember being tied to the cot, I remember pain. I remember hours of boredom and waiting, listening to the sounds of other children crying. I remember a woman wearing black and white.

Rough cloth, rough hands, pushing and poking and pulling.

Fear rushing through my body.

Pushing something hard into my body. Tearing, scratching pain up my bum. Pain. Movement down. Shit, my mess, my smell.

**Angry talk. Jesus, God and Satan.
Louder, shouting red face, spitting words.
I am the dirty devil child.**

**Poking those beads inside me and muttering unknown words.
Pulling them out quickly, stinging pain.**

She rages at me.

Brown shit and red blood on white cloth.

A nun, who was a nurse, abused me regularly. She gave me enemas, she used religious ritual, she believed I was evil because I did not get well, she was punishing me through the abuse. At the time I had undiagnosed swelling, pain and stiffness in my right knee joint. They had a splint fitted to my leg, which pulled it straight, but was very painful. I was tied down into the cot. I was there for "observation" until a diagnosis was made. Later, after exploratory surgery in a different hospital, I was diagnosed with Rheumatoid Arthritis.

**And next came the water, sometimes salt, hot and cold.
I was grabbed, taken to the bathroom, thrown into water, splashing,
stinging skin.**

**Metal jug filled and emptied over my head,
rushing water over my face.
Spluttering for breath,
aching throat from inhaled water,
reaching, attempting balance with my arms.
Big hands holding and pushing me down
under the water,
pain between my eyes
trying to grab air.
Big hands rub and hurt body,
fighting for air,
fighting for life and dignity.**

**Confusing adult feelings,
all the time those angry words.
Her touch full of hate,
fear for my life.**

Many survivors of child abuse report vivid memories of objects that they looked at during incidents of abuse, it is a common and effective coping

strategy when you have to tolerate painful, uncomfortable and humiliating acts, which are being done to your body.

Cold metals lines.

Grey puddle of spit on white sheet.

Cold cracked grey tiles.

I have described the abuse that I experienced repeatedly over a period of six months whilst I was in this hospital. During this time I was visited by my parents daily, and was also comforted by a young Irish women who worked at the hospital. It was summer and sometimes I was put outside, in a pram, under a tree. I remember looking up at the leaves and enjoying the sunlight streaming through the dense foliage. This was comforting and helped me.

This (next) experience was to have a profound impact on me:

Child with open eyes in the next cot, we stared looking at each other.

Men in white coats, agreeing quietly.

Metal bars go down.

Long arm reaches in, big hand covers his mouth and nose.

His eyes show alarm, body twitches and jerks.

His body stills, I watched the life leave his face.

Silence.

This time my fear doesn't rush, but sits in every part of my body, clamping me down.

Can they see me?

The big hand grasps the loose cloth at the boy's chest and lifts him up, his thin limbs dangle, his head bobs backwards.

He is gone, they have taken him away.

I take short silent breaths.

After this I don't want to use words, I don't want to be a human being.

Jean's artwork: putting the "self" back in the picture/narrative





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